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ABSTRACT

This second volume of the 1981 Report of the Select Panel for the Promotion of Child Health presents an examination of selected federal programs affecting maternal and child health and proposes detailed recommendations for federal legislative, regulatory, and other administrative improvements. Five federal programs, identified by the panel as having a particular positive impact on maternal and child health, are reported. These programs are Title V of the Social Security Act; Medicaid and EPSDT (Early and Periodic Screening, Diagnosis, and Treatment); WIC (Special Supplemental Food Program for Women, Infants and Children); Public Law 94-142 (Education for all Handicapped Children Act); and Community Mental Health Centers and Service Systems. The analysis of each program includes a summary of major recommendations, a brief description of the program (including an evaluation of its strengths and weaknesses), and a plan which includes specific recommendations for program improvements. The histories, purposes and accomplishments of 10 additional programs which play an important role in the delivery of health and health-related services are also briefly described. A full list of federal programs directly or indirectly related to maternal and child health is listed in Appendix A. (Author/MP)

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BETTER HEALTH FOR OUR CHILDREN: A NATIONAL STRATEGY

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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The Report Of The Select Panel For The Promotion Of Child Health

To The United States Congress And The Secretary Of Health And Human Services

1981

Volume II
Analysis And Recommendations For Selected Federal Programs

PS012110

THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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and Surgeon General
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DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF THE SECRETARY

SELECT PANEL FOR THE PROMOTION
OF CHILD HEALTH
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December 2, 1980

Honorable Patricia R. Harris
Secretary
Department of Health and Human Services

Honorable Edward M. Kennedy
Chairman, Subcommittee on Health and Scientific Research
Senate Committee on Labor and Human Resources

Honorable Henry A. Waxman
Chairman, Subcommittee on Health and the Environment
House Committee on Interstate and Foreign Commerce

Dear Secretary Harris, Senator Kennedy, and Congressman Waxman:

I am proud to transmit to you the report of the Select Panel for the Promotion of Child Health, in accordance with Public Law 95-626 which created the Panel.

The 17 members of the Panel and our staff have devoted an extraordinary amount of time, energy, and--we hope--wisdom to our task. Our commitment has reflected how seriously we have all come to take the opportunity offered us by the breadth of the mandate Congress assigned to us. The chance to design the foundations of a national effort to improve the health of our children has infused our work with excitement and zest. It has also permitted us to mobilize the contributions of hundreds of individuals and organizations throughout the country, engaged in large ways and small in understanding and serving the health needs of this country's children and families. The Panel, and the Nation, are profoundly in their debt.

We were impressed with the richness and diversity of available talent, competence and commitment, reflected in the accomplishments of a great variety of public programs and private efforts in communities throughout the country. We also became starkly aware of the extent of the unsolved problems that remain.

Our recommendations reflect a hardheaded analysis of serious unmet needs in child and maternal health, a recognition of past successes and future opportunities for effectively meeting these needs, careful consideration of the weaknesses and strengths of current Federal programs and policies, and a sober and pragmatic assessment of the capacity of our institutions to provide parents, professionals, and others working to improve child health with the scientific, financial, and organizational support they need.

Volume I of our report presents our major findings and recommendations.

Volume II contains specific recommendations for improving five major Federal programs with significant impact on child health:

- Title V of the Social Security Act
- The Special Supplemental Food Program for Women, Infants and Children
- P.L. 94-142: The Education for All Handicapped Children Act
- Medicaid and EPSDT
- Community Mental Health Centers and Services Systems

Volume III consists of what we believe to be the most comprehensive compilation of data on child health in the U.S. yet to be published.

We also submit a collection of background papers, listed at the end of Volume I, which were prepared for the Panel, and which we believe will be extremely useful to those who wish to become familiar in greater depth with selected aspects of the issues we have analyzed.

Some of our recommendations should be acted on immediately. Others are designed to be considered and implemented over a period of years. All of our recommendations are practical, and as specific and concrete as we have been able to make them.

The goals we set out encompass an extremely broad sweep of issues. In accordance with our congressional mandate we have addressed and analyzed issues and policies pertaining to the physical environment, health behavior, health services organization and financing, and health research. We did not try to go beyond these, although we are fully aware that other aspects of the social environment exercise a powerful influence on health. It is true that if we could eliminate poverty and racism in this country, if high quality preschool programs and community supports for families were more available, if teachers and schools were more effective, if we had full employment and every young person could look forward to productive work, our health indicators would improve significantly. Nevertheless, we have not focused on these issues, both because they are outside the Panel's mandate, and because we wish to help direct public attention to the extensive opportunities to improve child health by improving health policies and programs.

The Panel has asked me to call your attention to an additional problem we faced in defining our mandate. As you know, the legislation that established the Panel asked us to look at the health of "children and expectant mothers." Child health is obviously inseparable from maternal health. The health of the mother during pregnancy is unquestionably a major determinant of child health. But as we looked beyond purely physiological factors in child health, we found that our concerns must include fathers as well as mothers, both in relation to their role in the decision to conceive a child, and to their continuing role in providing nurturance, support, protection, and guidance to their children as they grow. Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on a child's health. We wish to be clear that our use of the term "maternal and child health," when we describe and analyze both needs and interventions, is in no way inconsistent with our conviction that fathers as well as mothers are central to raising healthy children.

We are grateful for the opportunity you have given us to engage in this work, and thank you for the help and support we have received from you and your associates in the course of our deliberations. We trust that the value of our efforts will prove to have justified the investment that the American public has made in the creation of this report.

I am sure you share with us the conviction that public policy, no matter how well conceived and carried out, can contribute only modestly to the vigor, grace, and joy we wish to see in our children's lives. But as our report makes clear, public policy and programs can mean the crucial difference, especially in the lives of the most vulnerable of our children.

We hope most profoundly that this report will contribute to shaping public policy in ways that will help all American families and communities to protect and promote the health of all of our nation's children.

Respectfully and sincerely yours,

Lisbeth B. Schorr

Lisbeth Bamberger Schorr
Chairperson

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†The Panel members who are representatives of the Department of Health and Human Services wish to commend the Panel as a whole for its thorough information gathering and careful analysis of child health problems. They believe the Panel's report is an extremely useful document. However, the specific programmatic and budget recommendations contained in the report have not yet been formally considered by the Department or by the Executive Office of the President. Thus, participation by Department representatives in the Panel's activities cannot be construed as an Administration endorsement of the recommendations.

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Volume II
Analysis And Recommendations For Selected Federal Programs

CHAPTER 1

OVERVIEW AND INTRODUCTION

In this volume of the report the Panel presents an examination of selected Federal programs affecting maternal and child health and proposes detailed recommendations for Federal legislative, regulatory, and other administrative improvements. These recommendations are aimed primarily at improving State and local program operations, though they involve action by Congress and the Federal executive agencies.

The Panel had a wide range of Federal programs on which it could choose to concentrate its efforts. In making its selection, the Panel took into account three factors: the relevance of the program's mission to maternal and child health; the program's impact on the health of children or pregnant women; and, most important, the need and opportunity for programmatic change, either because the program is not operating at its full potential or because modifications in it would permit major advances toward the national health objectives the Panel had identified. Based on these considerations, the Panel elected to focus its attention on the following five Federal programs:

- *Title V.* Enacted in 1935, Title V of the Social Security Act is the only Federal program concerned exclusively with the health of mothers and children. It provides Federal support to States to enhance their ability to "promote, improve, and deliver" maternal and child health care and crippled children's services, particularly in rural and poor areas. As part of their efforts, States currently are required to operate a "program of projects" in five areas: maternity and infant care, intensive infant care, family planning, care for children and youth, and dental care for children in low-income areas. The State and local programs supported by Title V have contributed significantly to improvements in maternal and child health over the past 45 years, including the decline in infant and maternal mortality and the reduction of disability in handicapped children.
- *Medicaid and EPSDT.* Medicaid was created in 1965 as Title XIX of the Social Security Act to reduce financial barriers to health care for the poor. A State-administered medical assistance program, Medicaid reimburses providers for covered services delivered to eligible beneficiaries. Since 1967, States have been

required to provide early and periodic screening, diagnosis, and treatment (EPSDT) as a mandatory Medicaid service to improve the health of low-income children through preventive health services. Medicaid has substantially eliminated the financial barrier to the most costly health care services and its EPSDT program has provided access to preventive health services to many children who previously had not obtained these services.

- *WIC.* In 1972, Congress enacted the Special Supplemental Food Program for Women, Infants and Children (WIC) as an amendment to the Child Nutrition Act of 1966. The program provides nutritious food and nutrition education to low-income, pregnant, postpartum, and lactating women, and to infants and children to the age of 5 who are at special nutritional risk. In addition, WIC is designed to serve as an adjunct to health care; in fact, it is the first food assistance program to tie eligibility to nutritional need and to require program sponsors to make health services available to their participants. Several studies suggest a positive correlation between WIC services and improved nutritional and health status.
- *P.L. 94–142.* In 1975, Congress passed P.L. 94–142, the Education for All Handicapped Children Act, in response to growing recognition by the courts of the rights of handicapped children, and the accompanying costs of providing needed services to them. The statute requires that "a free appropriate public education" be made available to all handicapped children from ages 3 to 21. It applies to all handicapped children regardless of the severity of their disabilities and their families' ability to pay for services. A basic requirement of the law is the provision of related services—such as physical and speech therapy, counseling services and medical diagnostic services—that a handicapped child needs to benefit from special education. In 1979, 3.9 million children received a public education as a result of this law—two or three times more than were served prior to its enactment.
- *Community Mental Health Centers and Service Systems.* In response to the need for a more unified mental health system, Congress enacted the Mental Health Systems Act in September 1980. It will become effective in FY 1982 and will replace the Community Mental Health Centers (CMHC) Act of 1963, which authorized Federal aid to States to help them construct and staff Community Mental Health Centers. The centers now provide a dozen different categories of mental health services, including inpatient, outpatient, consultation and education, and specialized services to children. CMHCs offer services to persons who traditionally have gone without them; indeed, there has been a substantial increase in the availability of mental health services to the indigent and to persons living in low-income areas.

Despite its concentration on these five programs, the Panel is fully aware of the contribution and achievements of the many other Federal programs that provide health care services to children and pregnant women. Among these is a group of 10 programs that has had a particularly

positive impact on maternal and child health. These include, for example, the Head Start program, Title X family planning services, Community Health Centers, and the various programs of the Centers for Disease Control. Unfortunately, the Panel was not able to devote the time it would have liked to scrutinize these programs more closely and to provide the type of indepth analysis it has for the five programs in chapters 2 through 6 of this volume. Chapter 7 presents a summary of these programs which, in concert with the five programs discussed in the preceding chapters, constitute the core of present Federal commitment to the health care of children and pregnant women.

In addition to the programs that are discussed in detail in chapters 2 through 6 and those reviewed briefly in chapter 7, there are numerous other Federal programs that are less directly related to maternal and child health, but are important sources of essential health care or related services. Such programs include the Civilian Health and Medical Program of the Uniform Services (CHAMPUS), the National Health Service Corps, the Food Stamp program, and the Alcohol and Drug Abuse Education program. Appendix A contains a full listing of Federal programs directly or indirectly related to maternal and child health.

SOME GENERAL FINDINGS

To enhance its understanding of the achievements and deficiencies of Federal maternal and child health programs, the Panel sought the views and opinions of State and local program administrators, congressional and Federal agency staff members, and academicians. In addition, the Panel reviewed numerous studies of the programs and asked specifically about program performance at public hearings in three cities (Denver, Atlanta, and Washington, D.C.) and site visits in two more (Jackson, Miss. and Chicago). Through this process the Panel gained insight not only into the programs themselves, but also into the broader policy issues in maternal and child health that must be confronted in the coming years. While these issues are touched upon in the chapters that follow, they are discussed in greater detail in volume I of this report.

Throughout its 18-month study, the Panel found widespread consensus about the interventions likely to be effective, the programs that work well and the obstacles that keep them from working better, the ways to get the most out of the money the Nation is already spending, and about improvements that could be achieved for relatively little more. It also found that a large proportion of the most troublesome child health problems can be prevented or ameliorated at reasonable and predictable cost by applying knowledge that is already at hand.

The Panel studied the problem of duplication of services and concluded, as many critics have, that the number and variety of programs create some duplication of services in a particular area, as well as some duplication of services to individuals. It found, however, that the duplication problem is less the case of an individual getting the same service two or three times, than it is too many programs operating

independently of each other, serving only a fragment of the population needing help or offering only limited assistance to people who need a great deal of it.

A far more basic problem in the Panel's view is that despite these numerous programs, a large number of infants, children, adolescents, and pregnant women still do not receive essential health care services. This point is best illustrated by the number of pregnant women—fully 25 percent of the total—who receive late, little, or no prenatal care at all. And this percentage is significantly higher among poor, black, adolescent, and unmarried women, those in rural areas, and those over 35—the very groups most likely to be at high risk of a poor pregnancy outcome. Similarly, a substantial percentage of handicapped children do not actually receive needed services even though an array of Federal programs such as P.L. 94–142, Developmental Disabilities, and the Supplemental Security Income Disabled Children's program are designed to help them.

Another critical concern is that many children and pregnant women receive services that either are of poor quality or are not part of continuing health care. For example, a substantial percentage of the children eligible for the EPSDT program have not actually been screened, or have not received screenings that are complete. Moreover, many of the medical problems identified through the screenings are not treated. The lack of continuing care is a particularly acute problem for children from low-income families. More than 18 percent of all children from such families lack a regular source of care compared with less than 6 percent of children from families with an annual income of $15,000 or more. As a result, children from poor families often receive care from sources that are only organized to provide care that is episodic and unnecessarily costly.

The fact that public programs have not been more successful in overcoming these problems is the result of numerous factors, many of which are unintended consequences of Federal legislation, regulation, and administrative policies. The most important of these factors are inadequate access to health care services, the absence of basic program information, lack of coordination among programs providing different levels of care and different types of services, and insufficient resources to support even essential maternal and child health services. Each of these factors is reviewed briefly below.

Inadequate Access to Care

To a large extent, inadequate access to care is caused by gaps in eligibility for health financing or service programs. There is a widespread but erroneous assumption, for example, that Medicaid has guaranteed the poor access to health care. Actually, Medicaid covers only about three-quarters of the poor, excluding some 7 million children in families that are poor according to Federal criteria. Medicaid coverage varies from State to State, including almost all poor and near-poor individuals in a few States, but only a fraction of them in others. In some States Medicaid covers only about 10 percent of all poor children and even then pays only about 10 percent of their medical expenses.

Even where eligibility is not an issue, children often do not receive the care they need because essential services are not available. The families of handicapped children falling within the purview of P.L. 94–142 know all too well the depth of this problem. Although these children are eligible for certain health, mental health, and medical evaluation services that are necessary to benefit from an individualized special education program, these services may not be available either from an existing source of care, such as a Title V Crippled Children's program, a Community Mental Health Center, or a local health department. The appropriate program may not exist in the area or it simply may not provide the needed service.

Access to services is also impeded by fragmentation among programs and policies. This fragmentation occurs among programs within the health care system and between the health care system and equally complex delivery systems in the related fields of social welfare, education, corrections, and rehabilitation. Evidence of fragmentation and the problems it causes for providers as well as consumers of services was encountered frequently in the Panel's hearings, site visits, and consultations. Consumers participating in both the WIC and EPSDT programs, for example, described the amount of work and school time that is lost because they must appear at clinics several times in order to receive the WIC nutritional assessment, an EPSDT screening, and routine obstetric and pediatric care, and appear on other days for treatment services. Service providers commented on the wasted time and resources.

The problem of fragmentation has become even more apparent with the advent of P.L. 94–142 in the schools, and with other programs such as the Developmental Disabilities program and the Supplemental Security Income Disabled Children's program. Under each of these programs, a designated agency is required to determine a child's needs and then design and carry out an individualized plan for meeting them. Although parental participation in the delivery of health and health-related services to children with special problems is critically important, too often families must sustain the entire burden of locating and coordinating the necessary services. This situation can cause a tremendous drain on a family's financial resources. There is, therefore, a pressing need to designate an individual in the responsible agency to manage each child's case, by making the appropriate contacts, explaining the problems and services needed, and assisting the family in obtaining appropriate services.

Other problems exist even where needed services are readily available. Sometimes, for instance, children are subject to different individual plans at once. This results in not only conflicts and confusion for the child and his or her family, but also an unnecessary waste of limited personnel and financial resources for those providing services.

Absence of Adequate Program Information

A second factor concerns the failure to develop data collection systems that would permit program accountability to Congress and to the general public, and facilitate the identification of necessary program improve-

ments. Data for these purposes have become even more important as financial resources for health care services have begun to dwindle. Indeed, continued or increased funding now requires documentation that the program has provided services and that the services are effective. Yet several of the Federal programs serving children and pregnant women have been deficient in their collection of this information. Community Mental Health Centers, for example, cannot identify the services they provide to children and the number or ages of the children they serve, and EPSDT only recently revised its reporting system to yield basic information about populations served and services rendered.

Insufficient data is a particularly serious problem for the Title V program. The problem can be traced in part to the 1976 decision to disband the Federal maternal and child health and crippled children's reporting systems and to rely instead upon the National Public Health Program Reporting System (NPHPRS) and the Bureau of Community Health Services Common Reporting Requirements (BCRR). Neither of these systems provides the information necessary for adequately monitoring State Title V agencies. Reduction in Federal expectations for data collection on maternal and child health services has led to laxity in some States, even though State authorities usually recognize that it is in their interest to have good information on needs and program performance. Another reason for inadequate State data collection of Title V services is simply lack of money.

Reporting problems can be compounded when various programs develop parallel and incompatible data bases to meet Federal accountability criteria. Conflicting definitions, classifications, and reporting categories created by different programs can make it almost impossible to retrieve relevant information and transfer the information needed to coordinate services among programs.

Lack of Coordination

The third factor leading to problems in the delivery of maternal and child health services is the general lack of structural coordination among programs, and the fact that no single agency at any level of government has responsibility and authority for planning and assuring the availability of the various health and related services needed by mothers and children. Programs created at the Federal level operate in isolated fashion, each with its own statutory requirements and regulatory policies, its own administrative structure, its own service delivery system, and even its own provider and staff constituency. Without major efforts to establish consistent and coordinated policies, each program tends to operate in a manner unrelated to the others.

It is on the local level that cooperative efforts among various agencies and programs can best be translated into effective action, linking together the resources of the health care delivery system with those of equally complex service systems in social services, education, corrections, and rehabilitation to meet the needs of mothers and children. In some communities, independent initiatives have had tremendous success. These

have been communities with strong support from local officials, enormous commitment on the part of professionals, and unusually persistent pressure from consumer and service advocates. Generally, though, local program coordination is dependent upon the involvement of relevant Federal, and particularly State, administering agencies.

Attempting to coordinate the State administration of service programs, however, is also a formidable task. Recently, a significant number of States have organized human service programs under a single umbrella agency with the hope that resources would be deployed for common objectives and duplication of effort would be reduced. But bureaucratic reorganization has not always helped, probably because some of the large, new structures are too cumbersome. In many States, for example, Title V and WIC program directors, although housed in a single agency, still are not working jointly on a plan for making health and nutritional services available in areas of greatest need.

Coordination of Federal activities for maternal and child health is equally difficult. Responsibility is diffused across various agency units within the Health Care Financing Administration (HCFA), the Public Health Service and the Administration for Children, Youth, and Families within the Department of Health and Human Services (DHHS), and also within the Departments of Education and Agriculture. The various programs administered by these agencies are, of course, reflective of multiple Federal policy objectives, yet since they are not sufficiently coordinated they do not always make the best use of resources. The interagency agreements reached by these agencies have made some improvements, and the Child Health Strategy recently initiated by the Secretary of DHHS to orchestrate the efforts of all departmental programs having an impact on maternal and child health has shown some results. But too often the agreements and coordinated activities have not gone far enough and their efforts have not been felt locally.

Insufficient Resources

All of these factors are compounded by a lack of sufficient resources to support the delivery of maternal and child health care services. While each of the programs discussed in this volume can be improved by better administration, clearer definitions of functions, and more effective coordination, most also require more adequate funding to achieve their full potential in improving the health of the Nation's children and mothers.

The effects of inadequate fiscal support cut across the entire system. When appropriations for specific Federal programs are below what they should be, for example, State and local authorities are often saddled with the responsibility of providing needed funds. This problem is particularly acute for the P.L. 94–142 program, where Federal appropriations have fallen considerably behind what they should be according to a State grant formula in effect since 1978. Similarly, when generalized sources of Federal support, such as revenue sharing moneys or support under Section 314(d) of the Public Health Service Act are cut, the effects are felt by those

implementing maternal and child health programs and policies as well as others. Effects on Federal programs also are significant when State and local tax support of programs is reduced. In the aggregate, the moneys which are used to support basic health services for children and pregnant women are not increasing at a rate sufficient to keep up with inflation and maintain even those levels of effort prevalent in the 1970's.

SUMMARY OF PROGRAM RECOMMENDATIONS

In reviewing the serious problems of limited financing, splintered oversight, and disincentives to program coordination which characterize the present system of Federal health care programs for mothers and children, the Panel considered the option of recommending that these programs be folded into a single piece of legislation, or repackaged so that funds could be awarded to the States as a block grant to be administered any way that made most sense given State and local realities. The simplicity of this idea was tempting, but on careful examination it was rejected by the Panel for two principal reasons.

First, the Panel believes that the Federal programs discussed in this volume represent an identifiable and potentially cohesive core of Federal effort to improve the health of children and pregnant women. In the aggregate, they are not so numerous as to defy coordination and sound management, and each has a legislative intent that the Panel believes is fundamentally sound. Each also has modes of implementation that can reinforce the effects of other major programs. The Panel believes that the limited number of programs discussed in this volume, if they come to be treated by Federal, State, and local policymakers as an interactive system for purposes of planning and implementation, contain all of the necessary attributes for attaining major objectives for maternal and child health at minimal feasible cost.

Second, and perhaps more important, are the potential dangers inherent in a general block grant approach to health program financing. As already noted, there are many inequities and inconsistencies in the existing system of health services to children and pregnant women. It is likely that a shift to extensive State control of health program expenditures, without clear Federal policy objectives and program standards, would permit this situation to persist and, in fact, intensify. What is needed, instead, in order to improve the health care system for children and pregnant women, is the establishment of national policy objectives, with Federal agencies working cooperatively to develop uniform service standards and individually to identify and monitor State program performance, while still retaining authority to fund local programs directly where States are not performing satisfactorily. The States, for their part, should retain substantial flexibility regarding the means by which national objectives are pursued.

What the Panel envisions, then, is the development of a more cohesive maternal and child health care system in which each of the core programs makes its own unique contribution to the health and well-being of the Nation's mothers and children. The Panel's recommendations for the five

programs it analyzed in depth are intended to achieve this purpose and, at the same time, to maximize the effectiveness of existing resources. These recommendations are characterized by a number of common themes, which include (1) clarifying and strengthening the complementary and mutually reinforcing responsibilities of these programs; (2) requiring essential components of local service programs; (3) targeting resources on populations in need; and (4) developing mechanisms for program oversight and accountability. These themes appear in the specific recommendations in the following chapters, and are summarized more generally here.

Complementary Program Functions

A primary strategy proposed by the Panel is to clarify the functional responsibilities among Federal programs and to assign to each program the resources and authority to carry out its responsibilities effectively. In each case, the Panel urges responsibilities that build on the program's historic and current strengths. At the same time, these functions are structured to be mutually reinforcing and aimed at common goals.

The Panel's recommendations for the Title V program are at the heart of its program improvement strategy. The Panel believes the Title V program should be given the lead role in developing resources and assuring quality for maternal and child health services. Working to achieve broad, federally established policy objectives, State agencies administering Title V should prepare a comprehensive plan to improve the quality and availability of health care for children and pregnant women statewide. This means assessing existing resources to determine their ability to meet maternal and child health service needs, identifying gaps in service quality and availability, and developing strategies to remedy current inadequacies. The Panel recommends that this Title V planning process be coordinated closely with the generic health planning required by the National Health Planning and Resources Development Act.

Beyond these planning functions, the Panel urges that State agencies administering Title V funds undertake a variety of new or expanded activities aimed at instituting changes required by the plan. These activities include coordination, technical assistance, quality assurance, and advocacy, as well as direct funding of local and regional service programs where they are not otherwise available. Just as the Title V planning effort would not be limited to Title V-supported programs, activities to promote the quality and accessibility of services should be broadly focused to include all actual and potential maternal and child health resources.

In quality assurance, for example, the Federal Title V agency would be responsible for establishing, in collaboration with appropriate professional and voluntary associations, minimum national standards for personnel, facilities, and delivery of care, and for setting minimum expectations for monitoring by the State agencies. State agencies, then, would further define quality standards and monitoring systems, based upon local conditions and needs, and would monitor the quality of services provided

to mothers and children by all publicly supported agencies. Any dual standard of care based on different sources of funding would be eliminated.

The Panel believes that implementation of its recommendations for Title V would have a substantial multiplier effect for the many other Federal programs concerned with maternal and child health. If State agencies administering Title V are assigned responsibility for developing and upgrading maternal and child health resources, educational agencies would be better able to arrange for handicapped children to receive the health services required as educationally "related services" under P.L. 94–142, and WIC sponsors would be better able to make available obstetric and pediatric services intended to be delivered to WIC participants in conjunction with food supplements. And, placing primary responsibility for standard setting with the Title V program would mean that the State agencies administering WIC and those administering P.L. 94–142 would be able to rely on the expertise of the State agencies administrating Title V for uniform standards of care. The same applies for the State Medicaid agency. Once common standards were adopted, Medicaid reimbursement of covered services provided under the auspices of these various programs would be facilitated.

The Panel believes that Medicaid should continue to serve as the major financer and purchaser of services for health care to low-income children and pregnant women until a broader national financing program is established. This requires that Medicaid be expanded to extend eligibility to all children and pregnant women who meet Federal poverty criteria, and to provide them a uniform national benefit package. In addition, Medicaid legislation should be amended to include a stronger component of Federal matching funds and to authorize better mechanisms for encouraging participation by appropriate providers, especially those offering continuing care. Strengthening Medicaid should produce more flexibility in Title V, thus reducing pressure to pay for needed services among low-income populations. Title V programs could reinvest these funds for such purposes as better primary care, improved coordination of services for the chronically ill and handicapped, stronger support for WIC-related nutrition assessments, and other means of enhancing the joint effects of the core programs in achieving national objectives.

Finally, the Panel recommends that WIC, Head Start, Title XX Day Care, and the P.L. 94–142 program all play an increased and coordinated role in early identification and case management of children with health problems. Although the primary purpose of each program is not the provision of direct health care, each is in a unique position to recognize health problems in children or pregnant women, refer them for care, and provide appropriate case management services. The WIC program, for example, which attracts large numbers of women and children who might otherwise not seek health care, is mandated to provide a nutrition and health assessment, and to make health care services available to its participants. To assure that this is achieved, the Panel makes specific recommendations to promote coordination between WIC providers and sources of continuing health care.

Head Start and Title XX Day Care programs also have a strong potential to find children with health needs and refer them to the health care system. Educational agencies do as well, since they are mandated under the Education for All Handicapped Children Act to undertake "child find" activities—reaching out to children before they enter school or preschool and identifying those with special educational needs, many of whom also require special health care. All of these programs tend to "find" the same children; therefore, they need to work together. Moreover, they should carry out their health service responsibilities in close coordination with Medicaid's EPSDT program, which screens many of these same children through private and public health care providers. State planning should strive to orchestrate a single approach to early identification of children with special needs, combining activities and resources of the various programs to ensure efficient service strategies.

Essential Components of Local Service Programs

Recommendations made throughout this volume are designed to promote particular local service program components that the Panel believes are critical to assuring the availability and accessibility of appropriate health care for children and pregnant women. These recommendations include:

(1) *Assurance that priority services are provided.* As discussed more fully in volume I, the Panel concluded that three sets of services are so important to the health status of children and pregnant women that access to them must be assured in every community. These basic, minimal services are: prenatal, delivery, and postnatal care; comprehensive care through age five; and family planning services. In addition, the Panel emphasized that treatment and support services to handicapped and chronically ill children must also receive special attention.

These decisions regarding the effectiveness and importance of certain categories of services are reflected in all of the Panel's major program recommendations. In its chapter on Title V, for example, the Panel urges that highest priority be given to planning, funding, and other program development activities aimed at assuring accessibility to the three sets of minimal basic health services for children and pregnant women and to special services for handicapped and chronically ill children. In its chapter on Medicaid and EPSDT, the Panel recommends that States be mandated statutorily to provide full coverage for all of the essential components of the three minimal sets of maternal and child health services and for many of the therapeutic services needed by children who are physically or mentally chronically ill. Proposed changes in the implementation of P.L. 94–142 and the new Mental Health Systems Act are also intended to extend access to the priority services locally.

(2) *Focus on prevention and health promotion.* The potential benefits of preventive care and health promotion—especially for mothers and young children—have been documented persuasively. Yet preventive care and health promotion measures are not receiving the emphasis they

deserve. The Panel's recommendations are intended to alter this by promoting various types of prevention and health promotion measures through the programs discussed in chapters 2 through 6. The Panel recommends, for instance, that Medicaid provide complete coverage for essential preventive services required by all children and pregnant women. Also, particular attention is given to activities that focus on primary prevention and early intervention by community mental health service providers.

(3) *Adequate mechanisms of case management to assure followup and continuity of care.* Case management is based on the assumption that for some service needs it is more efficient or feasible to help people take advantage of existing community resources than to restructure agency functions. Case management has proven very successful, for example, in helping parents of some Head Start children. A GAO report[1] documents the cost-effectiveness of the Child and Family Resource Center Program, which offers comprehensive family-oriented consultation in addition to traditional Head Start services.

In general, case management is a relatively inexpensive service that can maximize the impact of more expensive services. The Panel believes, however, that to be effective, case management activities must be designed so that a single lead agency or individual at the point of service delivery can assume responsibility for the various services required by each person. This is precisely the approach taken by the Panel in developing its proposals for improving the P.L. 94–142 program. As described in greater detail in chapter 5, the Panel recommends that local education agencies designate or employ an appropriately qualified health professional to manage the related services component of the individualized education program (IEP) that must be developed for each handicapped child who needs special education and related services.

(4) *Provision for coordinated outreach.* For the many families for whom services are inaccessible, health care programs sometimes must do more than provide an open door; they must take the initiative to find, educate, and help bring mothers and children into the health system. Such outreach efforts have proven effective in assuring that children and pregnant women enter the cycle of care at the appropriate time and that they receive appropriate followup care.

The Panel emphasizes the importance of outreach services throughout this volume and offers a number of proposals to enhance them. The Panel recommends, for example, that local Title V agencies and community mental health service programs be required to provide outreach services to children and pregnant women as a condition to receiving grant awards. With regard to the funding of these services, the Panel also recommends in its Medicaid chapter that the Federal matching rate for outreach services be increased substantially.

(5) *Coordination with other levels of care and types of services.* To better ensure both the quality and continuity of care, the Panel believes

[1]Comptroller General of the United States, General Accounting Office. *Report to the Congress: Early Childhood and Family Development Programs Improve the Quality of Life in Low-Income Families.* Publication Number HRD–79–40. Washington, D.C.: U.S. Government Printing Office, February 6, 1976.

that it is necessary for each of the major core programs to develop coordination mechanisms through which children and pregnant women can (a) be promptly and efficiently referred to providers of other levels of health care; and (b) move effectively among various maternal and child health and health-related services. Both of these policies are well illustrated in the Panel's chapter on Community Mental Health Centers and Service Systems. In it, the Panel recommends that mental health services include referral to a health provider, as appropriate, for a further health assessment or treatment intervention. Cooperative efforts are also encouraged among the mental health service system and the other systems in which children and their families function, including the education and the juvenile justice systems.

To promote coordination among health service programs, the Panel proposes, for example, that State agencies administering the WIC program be required to adopt a number of standards and procedures established by the Title V program. The Panel recommends that for some services, uniform accounting procedures should be developed and used by the WIC, Title V, and Medicaid–EPSDT programs. Implementing these and other similar policies will help to assure service availability and quality while reducing program costs.

Another theme undergirding the Panel's program recommendations is the targeting of resources to all mothers and children who need services. Throughout this volume the Panel has proposed policies that would direct resources to populations and individuals in need. In some instances, this has meant recommending that public funds be more narrowly focused on populations known to be at special risk. In others, it has meant recommending that a category of eligibles be broadened to include needy individuals who otherwise would be without access to essential health care services. It should be mentioned, however, that over the long run the Panel believes health programs should be inclusive rather than exclusionary, and that, in particular, a financing program providing universal entitlement to children and pregnant women is preferable to one directed solely to women and children who are poor.

To ensure that resources are allocated in the immediate future where they are most needed and will do the most good, the Panel recommends revisions in policies governing program eligibility, particularly those for Medicaid and WIC. It urges, for example, that Medicaid eligibility be extended to all pregnant women and all children to age 18 whose adjusted family income is at or below the federally established poverty level. And to minimize disruption in continuity of care, the Panel recommends further that Medicaid eligibility for children and pregnant women be retained for 1 year following a completed health assessment regardless of any change in income. With respect to WIC, the Panel proposes that income eligibility criteria be consistent with nationally established standards. Although the Panel's proposal would permit States to exercise flexibility in selecting a specific standard to apply, it would ensure that WIC benefits would be targeted at all women, infants, and children from low- and moderate-income families.

The Panel's position on the allocation of resources is also reflected in recommendations to redefine program objectives. This is the case with the

Title V program. While the Panel endorses the overriding goal of the Title V program—to promote, improve and deliver maternal and child health care services—it believes that the program's more immediate objective should be to focus its resources on those geographic areas without adequate maternal and child health services. Thus the Panel proposes that in funding direct service programs, State agencies administering Title V should be directed to give special emphasis to assuring the availability of needed services in medically underserved areas, especially those with a high concentration of low- and moderate-income families.

Mechanisms for Program Oversight and Accountability

The final theme common to the Panel's recommendations for each Federal program is the establishment of mechanisms for oversight and accountability. To ensure that maternal and child health care programs are operating effectively and efficiently, the Panel believes that two complementary measures must be taken at all levels of government. They are:

(1) *Improvements in data collection, reporting and monitoring.* The primary goal of the Panel's proposals in this regard is for programs to be better able to identify Federal, State and local expenditures, track the number of services provided and the persons who receive them, and ascertain whether program objectives are achieved. These functions, which are increasingly important in an era of fiscal restraint, require the collection and analysis of relevant data that can be presented in a manner that meets various policy needs.

Because the Title V program is the cornerstone of the Panel's overall strategy to improve health care for children and pregnant women, data collection for the Title V program has been given special attention. In its Title V chapter, the Panel emphasizes the need to collect certain types of data and to design a practical reporting system that would allow Federal and State program administrators to assess program performance and to manage Title V funds more effectively. To ensure coordination among different programs, the Panel recommends that this reporting system not be developed in a vacuum; the system should be consistent with other relevant reporting systems, such as those for WIC and EPSDT.

Routine monitoring by Federal and State agencies is equally important in measuring program performance. It is also essential in order to learn whether services are actually being delivered in accordance with statutory and administrative requirements. Both objectives can be achieved in the area of mental health services for children, for example, through the implementation of the Panel's proposal that the Secretary of DHHS be required to report to Congress on the progress being made to extend appropriate mental health services to all children. In the Panel's view, this report should contain information on the type and number of services being provided, the extent to which these services are meeting identified needs, and the standards used in providing the services as well as other

relevant material. Periodic assessments of this type will help to assure that the health needs of children and pregnant women are being met adequately.

Here, too, however, efforts should be made on a cooperative basis, where appropriate, by both Federal and State agencies administering the various programs analyzed in this volume. Monitoring procedures for the health services component of the WIC program, for instance, should be developed and performed in cooperation with agencies administering the Title V program.

(2) *Establishment of advisory bodies.* The Panel believes that maternal and child health advisory bodies should be established at all levels of government to provide visibility and public oversight and accountability to the efforts of all maternal and child health programs.

Locally, these bodies should be provided with the opportunity to have direct input on the operation of specific programs. With regard to mental health services, for example, the Panel recommends that CMHC advisory boards include both lay persons and professionals with a demonstrated interest in providing maternal and child health services to children.

At the State level, the responsibilities of such bodies should be broader in scope than is the case with local advisory groups. State councils should serve primarily as coalitions to support and assist State Title V directors and other agency personnel in ongoing program and policy formation. These councils, like the local advisory bodies, should include consumers knowledgeable about maternal and child health issues.

At the Federal level, the Panel believes there is a need to create a special advisory body—the National Commission on Maternal and Child Health—which will have among its functions responsibility for reporting to Congress and the Secretary of Health and Human Services on the health status and unmet service needs of mothers and children, and recommending policy changes in Federal maternal and child health programs to improve their effectiveness and to enhance coordination among programs. To keep Commission members better informed as to what is taking place in maternal and child health services at the State level, the Panel proposes that the Commission include at least one member of a State Maternal and Child Health Council.

PLAN OF VOLUME II

The following five chapters take up in detail Title V, Medicaid and EPSDT, WIC, P.L. 94–142, and the recent Community Mental Health Centers and Services Legislation. Each has the same general format: a summary of recommendations; a brief description of the program being analyzed, including an evaluation of its strengths and weaknesses; and a plan for program improvements, including specific recommendations. Chapter 7 briefly describes the other core programs.

Because the recommendations are quite specific, and the Panel decided it did not wish to trade away specificity for complete consensus, several

dissenting views to particular ideas put forth in the various chapters appear in appendix C. The Panel regards it as significant that in a volume of this scope and detail, dissent was as slight as it turned out to be.

Appendix A, as mentioned previously, is a summary of Federal programs providing health and related services to children and pregnant women.

Appendix B acknowledges the many people who assisted the Panel in the preparation of volume II.

CHAPTER 2

TITLE V

MAJOR RECOMMENDATIONS

- Establish as priority services for all Title V activities:
  - —comprehensive prenatal care, delivery, and postnatal care;
  - —comprehensive primary and preventive care for children from birth through age 5;
  - —family planning services; and
  - —specialized services for handicapped and chronically ill children.
- Require State Title V agencies to develop and implement a plan aimed at improving the availability, accessibility, and quality of a comprehensive and coordinated, statewide system of maternal and child health services.
- Establish within the Public Health Service a new Bureau of Maternal and Child Health Services responsible for administering the Title V program and for promoting Federal policies to improve the delivery of maternal and child health services.
- Improve Federal and State mechanisms and procedures for assuring program accountability and enforcing Federal requirements.
- Establish a National Maternal and Child Health Commission to report to Congress and the Secretary of the Department of Health and Human Services on Federal programs and regulatory policies that have a direct impact on the health of children and pregnant women.
- Increase the Federal appropriation for Title V to assure that a greater proportion of children and pregnant women receive the preventive, primary, and specialized care they need.

PROGRAM DESCRIPTION AND ACCOMPLISHMENTS

Title V of the Social Security Act[1] authorizes the only Federal program concerned exclusively with health care for mothers and children. It

[1] Title 42 U.S.C. Sec. 701 *et seq.* (1976 & Supplement II 1978).

provides Federal support to the States to enhance their ability to "promote, improve and deliver" maternal and child health care (MCH) and crippled children's (CC) services, particularly in rural areas and areas of severe economic distress. Funds are to be used for: (1) services to reduce infant mortality and promote maternal and child health and, (2) services and facilities to locate, diagnose, and treat children who are crippled or suffer from potentially crippling conditions.

The Title V program has a long and distinguished history. It was enacted by Congress in 1935 and originally administered by the Children's Bureau. The intent of Congress in passing this legislation was to improve the health status of mothers and children in areas of greatest need through a program of assistance to the States. In the 45 years since Title V was enacted, the purpose of the program and the broad flexibility accorded the States have remained relatively unchanged.

Some significant modifications have occurred, however, in Title V since its inception. The most important began in 1963 when Congress adopted the first in a series of amendments establishing special project grants for specific maternal and child health activities in low-income areas. The 1963 law provided grants to State and local health departments for Maternal and Infant Care (MIC) projects aimed primarily at reducing mental retardation and infant mortality through prenatal, perinatal, and postpartum care, and family planning services. In 1965 other amendments authorized special project grants to provide comprehensive health services to children and youth through State and local health agencies and other public or nonprofit organizations. In 1967, Title V was amended again, this time to provide special grants for dental services to children. Until 1974, these project grants were administered federally. In that year, as required by the 1967 Title V amendments, direct administrative responsibility for these projects shifted from the Federal Government to the designated State maternal and child health unit.

The 1967 amendments also linked Crippled Children's Services and Medicaid in the provision of Early Periodic Screening, Diagnosis, and Treatment (EPSDT). Medicaid was mandated to provide EPSDT as a covered service for all children, and the CC program was required to provide for the early identification of children who need health services, and for the health care and treatment needed to correct or ameliorate defects or chronic conditions. The amendments also provided that Medicaid, CC programs, and MCH programs as well, were to enter into agreements for the delivery and reimbursement of these services.

Today, each State is required to operate what the law terms a "program of projects" in each of five areas: maternity and infant care, intensive infant care, family planning, health care for children and youth, and dental care for children. The statute directs States to establish these projects in low-income areas and to provide "reasonable assurances" that the broad objective for each type of project is met. As interpreted by regulation, a single project of each type satisfies the minimum Federal requirement.

Additionally, of course, States are required to provide services in maternal and child health care and services to crippled children. These services, plus the program of projects, are the basic service requirements for an approved State Title V plan. Regulations provide additional guidance, particularly in the area of quality assurance, but establish few specific program and planning requirements.

The Federal appropriation for Title V is allocated by means of a complex formula prescribed by statute. The law provides that 90 percent of the Federal appropriation be used to support MCH and CC services and that up to 10 percent be retained by the Secretary of the Department of Health and Human Services (DHHS) for research and training activities. In addition, the law requires that at least 6 percent of the total appropriation must be used for family planning activities either under general or special projects grants.

The allotments for both MCH and CC services are divided into two equal parts, termed Fund A and Fund B, and allocated according to a similar method. For both services, Fund A moneys are earmarked for the States and require a dollar-for-dollar match. States are first allotted a basic grant of $70,000 and then an additional amount intended to reflect relative need based on population. In the case of the MCH Fund A, this amount is based on the number of live births, and in the case of the CC Fund A on the number of children under 21 years of age.

Fund B moneys are awarded to certain nonprofit institutions as well as to the States, and carry no match requirement. For both MCH and CC services, an amount of $5 million is allocated from Fund B for States and institutions of higher learning to establish projects to serve the mentally retarded. Of the remainder, at least 75 percent is apportioned among States according to need based upon *per capita* income and either the number of live births (MCH) or the number of children under 21 (CC) with rural States given twice the weight of urban States. These funds are intended to assist States in carrying out their State plans. The remaining 25 percent or less, known generally as "Reserve B" or "RB" Funds, is retained at the Federal level for grants to special projects of regional or national significance.

Since FY 1978 Congress has provided an annual appropriation of approximately $400 million for all Title V activities. Although the authorizing legislation leaves the Secretary of DHHS discretion in determining how to allocate funds between the MCH and CC services, the congressional appropriations process has produced a line-item budget for each of these services, roughly two-thirds for MCH and one-third for CC.

Title V is now administered federally by the Office for Maternal and Child Health (OMCH) within the Bureau of Community Health Services (BCHS). The Bureau is in the Health Services Administration (HSA) of the Public Health Service (PHS). State administration of the MCH program is the responsibility of the MCH unit within each State's health agency. Most of the Crippled Children's Services programs also are administered through State health agencies. About one-fifth, however, are

administered by other State agencies, including welfare departments, social service departments, and, in three instances, State universities. State administering agencies generally operate their programs through local, district, or regional health departments, but many enter into contracts with other agencies as well.

The activities of State Title V agencies generally span a wide range, including training, consultation, standard-setting, quality assurance, advocacy, and planning, as well as the direct provision of preventive, primary, and specialized health services. Although all States are engaged in each of these activities to some extent, their role in providing and supporting direct services is especially varied.

Within each State a portion of the MCH and CC funds is retained by the State Title V agency for a variety of purposes and the remainder is distributed to agencies and individual practitioners. MCH funds, in many States, go to local health departments—some administered by the State itself and others by local governments. These funds may be distributed by formula, project grant, or other mechanism. As a result, States have different degrees of control over the use of MCH funds locally.

In addition to the elements of the program of projects, most State MCH programs support maternity clinics and well-child checkups, immunization programs, vision and hearing screenings, school health services, and a variety of other traditional maternal and child health services. Some States also have used their MCH funds, usually combined with other funds, to develop comprehensive care services for children and pregnant women.

Funds for crippled children are used to provide direct services in one of three ways: through State-operated and staffed clinics, under contractual or fee-for-service arrangements with private practicing physicians, or most often, by a combination of full-time State staff and part-time private physicians working together in State-operated clinics. Regardless of the method used, however, all CC programs are designed to provide diagnostic, evaluation, treatment, and rehabilitative services to children with handicapping or chronic conditions, and all take a multidisciplinary approach to care. State programs nearly always employ psychologists, nurses, and physical and speech therapists whose services are coordinated with those of the physician. Other health professionals may be on staff as well. Perhaps most importantly, the CC programs assume responsibility for case management; they prepare an individualized service plan, arrange for the delivery of needed medical, health, and support services, and modify the plan as needed to reflect changes in the child's condition.

Using their Title V allocation in combination with funds from other sources, State Title V agencies provided health care to some 16 million low-income women and children in FY 1978. These services were provided by both State and local health departments.[2] In addition, almost 400,000 individuals received medical care, over 41,000 received dental

[2]Data from the National Public Health Program Reporting System (NPHRS). NPHPRS has estimated that in 1978 approximately 43 percent of the maternal and child health expenditures of State agencies came from Federal Title V funds.

care, and more than 300,000 received other health services from MIC and C&Y projects.[3]

Besides providing assistance to the States and coordinating efforts with relevant Federal agencies, the activities of the Federal office, OMCH, are largely concerned with the administration of the grant programs in special projects, training, and research. Decisions about how these grant funds are spent are made by OMCH, generally in consultation with other Federal officials, the regional offices, State officials, and in the case of the research funds, on the advice of a peer review group.

A large portion of the MCH Reserve B funds are currently allotted to special projects in two program areas: Improved Pregnancy Outcome (IPO) and Improved Child Health (ICH). Under these programs, the States receive project grants and technical assistance to strengthen their capacity in these areas. Reserve B funds for CC services are used to support a variety of clinical programs in all States and to provide several States with Interagency Collaborative Grants to work with State educational agencies in the implementation of the Education for all Handicapped Children's Act, P.L. 94–142.

In the area of training, Federal grants are aimed at educating competent administrators and practitioners through interdisciplinary training. Priority for funding is currently given to training in areas such as genetic screening and counseling, perinatal care, adolescent services, and services to multihandicapped children. In recent years, nearly 8,000 health professionals have received long-term and extended short-term training annually.

Finally, the research grant program supports projects that can lead to improved methods of delivering MCH and CC services. The current emphasis is on adolescent health, child abuse, inborn errors of metabolism, congenital malformations, early case finding, and family counseling. Usually 50 to 55 grants are active at any one time.

Title V program efforts at all levels of government have contributed significantly to improvements in maternal and child health over the last four and a half decades. Panel members and many independent evaluators believe that the program has helped to bring about the decline in maternal and infant mortality, the reduction of disability in handicapped children, and the general improvement in child health status. Its influence has been both direct—through the provision of services by local health departments, schools, and especially Maternal and Infant Care and Children and Youth projects and crippled children's clinics—and indirect—through the establishment and enforcement of standards of care.[4]

Despite the proliferation of other programs to serve low-income women and children, including the handicapped, Title V-funded agencies remain

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[3]Data from Bureau of Community Health Services Common Reporting Requirements (BCCR) system. For additional program and funding data, see L. Klerman, "Maternal and Child Health and Crippled Children's Services of the Social Security Act: Problems and Opportunities." In *Better Health for Our Children: A National Strategy*, volume IV. Washington, D.C.: U.S. Government Printing Office, 1981.

[4]Wallace, H. M. "Status of Infant and Perinatal Morbidity and Mortality—A Review of the Literature." *Public Health Reports* 93(4), Washington, D.C., U.S. Government Printing Office, 1978.

the only source of care for such groups in many areas. Without maternal and child health services, fewer women would have received health care during pregnancy, delivery and the postpartum period, and fewer infants would have had care during their first year of life. Similarly, without the crippled children's program, many crippled children would not have received the case management and ongoing care and treatment they required.

BASIS FOR RECOMMENDATIONS

Although the Title V legislation requires States to extend and improve services aimed at reducing infant mortality, promoting the health of women and children, and locating and caring for children with handicapping conditions, the structure of the program, its level of support, and its current operation are inadequate to achieve its stated purposes. Indeed, recent statistics and reports document that:

- Many women, especially those at highest risk, receive no prenatal care at all or they receive it late in pregnancy.[5]
- Many high-risk pregnant women do not deliver at centers that are equipped to meet their specialized needs.[6]
- Many newborns in need of neonatal intensive care unit treatment do not receive it either because such a unit is not available or because personnel are not trained to use it.[7]
- Many infants and children have no regular source of primary care.[8]
- Many young children still do not receive all recommended immunizations.[9]
- Many children with handicapping conditions do not receive the services they need to function at their optimal levels.[10]

No single program or combination of programs could be expected to meet the health care needs of *all* children and pregnant women, yet the Panel believes that Title V's broad mandate, long history, and significant investment of Federal and State funds could have produced a more effective system of health care services for children and pregnant women,

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[5]National Center for Health Statistics. *Prenatal Care, United States, 1969–1975.* DHEW Publication Number (PHS) 78–1911, September 1978.

[6]Comptroller General of the United States. General Acccounting Office. *Better Management and More Resources Needed to Strengthen Federal Efforts to Improve Pregnancy Outcome: A Report to the Congress.* Washington, D.C.: U.S. Government Printing Office, 1980.

[7]Comptroller General of the United States. General Acccounting Office. *Better Management and More Resources Needed to Strengthen Federal Efforts to Improve Pregnancy Outcome: A Report to the Congress.* Washington, D.C.: U.S. Government Printing Office, 1980.

[8]See *Better Health for Our Children: A National Strategy,* volume III, Table 26–28, 30. Washington, D.C.: U.S. Government Printing Office, 1981.

[9]See *Better Health for Our Children: A National Strategy,* volume III, Table 23. Washington, D.C.: U.S. Government Printing Office, 1981.

[10]Klerman, L. "Maternal and Child Health and Crippled Children's Services of the Social Security Act: Problems and Opportunities." In *Better Health for Our Children: A National Strategy,* volume IV. Washington, D.C.: U.S. Government Printing Office, 1981.

and thus even greater reductions in infant mortality. While poverty and lack of education may be significant factors associated with infant and maternal morbidity and mortality, some exceptional comprehensive health care programs have had a major positive impact on such problems, even when underlying conditions remained unchanged. The substantial differences in rates of morbidity and mortality in areas with similar socioeconomic characteristics suggest differences in health care services, including Title V operations, and the opportunity for vital improvements.

When the Title V program was initiated, it was commonly assumed that States would create strong maternal and child health units in local health departments to provide complete health services for children and pregnant women. In fact, this has not happened. Even after the program of projects became a requirement, States generally did not promote the statewide development of primary care programs based on the MIC and C&Y project models. Instead, States accepted the traditional public health clinic model as the arrangement for Title V services. As a consequence, Title V services far too often are provided through separate and discrete programs, usually preventive in focus—a perinatal program, an immunization program, a V.D. program, a well-baby program, and so on.

With the exception of the Maternal and Infant Care and Children and Youth models, which are required to provide treatment services, there are great variations in the way that Title V beneficiaries receive the care they require. The Panel found that in some States, primarily in the South, local health departments provide medical care for sick children from low-income families through public clinics and hospitals. In other regions, sick children usually are referred to either private physicians or hospital outpatient departments for treatment services, the cost of which, in certain situations, is reimbursed by the local or regional health department.

The inequities are perhaps even more striking for handicapped children. According to OMCH, all crippled children's programs include services for handicapped children who need orthopedic or plastic surgery, and nearly all include services for certain chronic illnesses, and for hearing and vision problems requiring surgery. But there nevertheless are great variations in coverage for the 125 established diagnostic categories. In some States, children with chronic otitis media, for example, may be covered under the CC program and in other States they may not; the hearing loss for children who cannot receive appropriate treatment may be significant.

Beyond gaps in service coverage, there are serious inconsistencies in eligibility. By regulation, preventive and diagnostic services must be available to all women and children at no charge; however, States and even localities are free to set their own income eligibility requirements for all other services. The Panel is concerned that this latitude, combined with differences in Medicaid eligibility criteria among States, creates an unfair situation: women and children may be eligible for Title V services in one community but not in another, or in one State but not another.

The Panel is concerned that in some communities racial and ethnic prejudice also creates barriers to care. As with health care generally, certain groups of beneficiaries may be discouraged from participating in Title V programs because of discourteous and unfair treatment; and in some instances, opportunities for receiving Title V services may simply be

foreclosed to them. These concerns have been mentioned in the literature and cited by practitioners and client advocates. Children's Defense Fund (CDF) staff note, for example, the common and subtle discrimination of some private providers who refuse to treat minority families, and who refuse to join in cooperative arrangements with health departments.[11] Similarly, language barriers in Title V projects can also limit accessibility, particularly for Hispanics, Native Americans, and Southeast Asians.

Many inequities in access to care and services are due to the absence of statewide planning for maternal and child health needs. States have relative freedom in deciding the populations they wish to serve and the services they wish to provide. For the most part they have not allocated service funds on the basis of needs assessments in each service area. Their decisions, instead, have often been guided by political considerations. Many States, for example, distribute MCH funds to counties according to a set formula, and many cover diagnostic categories for services to handicapped children in response to consumer and provider constituencies. The result has been occasional duplication of services between Title V and other agencies in the same area and, more often, serious gaps in services or no programs at all in areas of pressing need.

States, however, are not required to undertake comprehensive planning for the distribution of Title V funds.[12] Even the requirements for the State plan document are minimal. Although a State plan for the use of Title V funds must be approved before the funds are allocated, there is no required format for these plans. Since 1968, Federal and regional offices have not even required that plans be submitted. The plans must be available in State Title V agencies for inspection by regional officials, but the inspections seem to be limited to checking for the inclusion of information necessary for conformance with certain statutory requirements. Even when plans are checked for the presence of required information, the content of the information is not reviewed. The Panel believes that the absence of adequate mechanisms for assuring the most effective use of Title V funds has impeded the ability of the Federal Government and the States to pinpoint problems and develop solutions.

The lack of accountability is of particular concern to the Panel. Central to the problem is the inadequacy of current reporting systems—the National Public Health Program Reporting System (NPHPRS) and the Bureau of Community Health Services Common Reporting Requirements (BCRR)—neither of which provides the information necessary for adequately monitoring State Title V agencies. Not all States report under these systems, and the data they do report include services provided with funds from Title V and funds from other sources. Some pertinent information is not collected at all. NPHPRS, for example, does not collect such information as the racial characteristics of patients and the types of services delivered. The collection of management information and data on

[11]Information obtained from interviews with CDF staff.

[12]Recently, however, OMCH has begun to encourage State Title V agencies to undertake planning activities. "Guidelines" for both an Objectives and Activities Report and an Annual Program Performance Report discuss measurable objectives, ways to accomplish them and to evaluate performance against them. These guidelines emphasize health services for all mothers and children and cooperative arrangements with other health-related programs.

specific categories of care that have been used for many years has been perpetuated without any overall policy direction. Moreover, both data systems are only minimally compatible with Federal and State requirements for other programs aimed at the same populations—such as WIC (the Special Supplemental Food Program for Women, Infants, and Children), EPSDT, and Family Planning—leading to expensive, possibly overlapping reporting systems.

The accountability problem is further aggravated by the fact that States are permitted to meet their financial match requirements with in-kind services. This results in the diffusion of Title V funds to support activities across many health department programs, including those only peripherally related to women and children, and also permits the support of general health department overhead.

The Panel is also concerned that Federal staff members at the central and regional levels are not sufficiently monitoring the States to assure that Federal and State matching funds are used to further the purposes of Title V. Several reports[13] note the absence of State documentation to substantiate that matching funds are, in fact, allocated to activities approved in the State plan, even when regional health authorities identify this as a problem. There is also no monitoring system to assure that funds channeled into States are being used for programs and services strictly related to maternal and child health.

The Panel concludes that most problems with the Title V program are largely attributable to the vagueness of the authorizing legislation and to insufficient funding support. The Title V program rests on a statutory foundation that specifies broad goals but provides little in the way of requirements for achieving them. Because of this vagueness it has been almost impossible to tell a State it was doing something it should not—or failing to provide a service that it should.

Moreover, there are no appropriate sanctions or other enforcement mechanisms. Federal legislation authorizes the withholding of Federal funds for noncompliance with statutory requirements, but these requirements are minimal. Additionally, of course, the sanction is not likely to be imposed, since a full withholding of funds would harm the women and children who need services.

Financial issues have created further complications. The Panel believes the Federal funding has never been adequate to the overall Title V mandate. As a result, States have been forced to omit essential services and OMCH and the Federal regional offices have been limited in staff resources to provide needed consultation and assistance.

The inadequacy of the total Federal funding level has been compounded by inequities in the distribution of funds to States. The Title V basic grant formula for MCH and CC programs has always favored States with large rural populations. When Congress shifted direct administrative responsibility for project grants from the Federal Government to the designated MCH State units in 1974, Federal funding for existing projects

[13] See, for example, U.S. Department of Health, Education, and Welfare, Office of the Inspector General. "Report on Audit of MCH Programs Administered by the State Board of Health, Indianapolis, Indiana," August 1978.

was folded into the MCH State allocation. This brought many rural States a windfall and left some large industrial States shortchanged, because rural States are favored in the general MCH funding formula and because urban States previously had the bulk of project grant funds. To compensate, Congress provided for Supplemental "Section 516" funds to be distributed among States receiving fewer dollars under the new arrangement. But these States have not received an increase in funds for many years—despite their significant populations of inner-city poor—while rural States have.

Many of the problems with Title V date to its origin. The historic roots of Title V produced program directions that are no longer in keeping with health care trends. When the Social Security Act was passed in 1935, the social climate was not ready for a large-scale governmental role in the financing and provision of medical care. Most Title V agencies developed preventive care programs, such as prenatal care, well-child care, immunizations, vision and hearing screening, and most physicians were supportive of their doing so. On the other hand, at least in most States, treatment was reserved for the private physician or the hospital. The MIC and C&Y projects had to be initiated by Federal grants to change this pattern. Even when the projects were made an integral part of the State Title V program through the program of projects, relatively few States with funds available chose to expand the comprehensive care model statewide.

As gaps in services became apparent, Congress created new, separately funded programs, such as EPSDT, WIC, and Family Planning project grants, rather than strengthening the Title V mandate or increasing its appropriation. Originally, funding for the Community Health Centers, Head Start, and other Federal initiatives in service delivery flowed directly from the Federal Government, through the regional offices, to local sponsors. In most cases, the State health departments had no part in the decisionmaking process. Recently, OMCH has been urging State Title V agencies to become involved with the Federal projects through consultation, planning, and technical assistance activities, but it will take time to overcome many years of inattention and interprogram hostility. As a General Accounting Office report cites, the multiplicity of congressionally mandated child health programs, the fragmentation of efforts among several Federal agencies, and the lack of effective coordination remain impediments to the delivery of comprehensive, high-quality services for children and pregnant woman.[14]

Policies adopted by the Administration in the early 1970's to reduce the authority of Federal agencies also shaped the Title V program. To offer more flexibility to States and remove what were perceived as excessive administrative burdens on them, many mechanisms for accountability and reporting were abolished, and Federal staff positions responsible for overseeing these functions were eliminated. Now the need to restore accountability and provide effective Federal leadership is critical.

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[14]Comptroller General of the United States. General Accounting Office. *Better Management and More Resources Needed to Strengthen Federal Efforts to Improve Pregnancy Outcome: A Report to the Congress.* Washington, D.C.: U.S. Government Printing Office, 1980.

PLAN OF ACTION

Despite these problems, the Panel is convinced that the Federal, State, and local agencies administering Title V could provide effective leadership in improving health care for children and pregnant women. Given a clear statutory mandate and increased Federal support, the Panel believes these agencies can make major strides in achieving the goal of a comprehensive and coordinated system of high-quality maternal and child health services—a system that will assure children and pregnant women access to the services most essential to their health and development, and that will make available the health services required for the success of other federally funded programs, including WIC, P.L. 94–142, Head Start, and Medicaid's EPSDT.

The Panel's basic approach to strengthening the Title V Program is: first, to assign State agencies broad responsibility for planning, advocacy, quality assurance and other activities to promote the quality and availability of maternal and child health services throughout the State; and second, to direct these agencies to use grant funds to support certain needed services, especially in medically underserved areas. A complementary and supportive role is proposed for the Federal Title V agency, including setting minimum service and provider requirements, providing technical assistance, and monitoring State activities to assure all Federal and State objectives are met. To further enhance the Title V program, the Panel also recommends:

- the creation of national and State advisory committees on maternal and child health
- improvements in Federal and State mechanisms to assure accountability
- an increase in Federal funding for Title V as well as a simpler and more equitable approach to distributing these funds

To implement these recommendations, the Panel advocates major revisions of the Title V legislation, as well as regulatory and administrative policies to carry out the proposed statutory changes. The Panel recognizes that some of its proposals could be implemented under existing legislative authority. However, the combined need to recast the purpose of the program and to establish mechanisms and administrative responsibilities to ensure that these purposes are achieved does warrant legislative action. Congress has reviewed and modified the Title V legislation approximately every 10 years. The last amendments to the law were enacted in 1967; therefore, the Panel believes it is appropriate that Congress reassess the Title V program and its legislative structure at this time.

The Panel urges that new legislation include as the purpose of the Title V program the development of a comprehensive and coordinated system of health care for women and children, with special emphasis given to four priority services. These are:

- comprehensive prenatal, delivery, and postnatal care
- comprehensive primary and preventive care for children from birth through age 5
- family planning services

- specialized services, including diagnostic, evaluation, treatment, and case management services, for handicapped and chronically ill children

A New Role for State Title V Agencies

The legislation should also set out the mission of the State Title V agencies: to develop and implement a plan to assure statewide accessibility to high-quality comprehensive maternal and child health care services.[15] To carry out this mission, State agencies should be required to plan and promote improvements in the quality, availability, and accessibility of maternal and child health care services for all women and children, and to provide grant funds to support required services, especially in medically underserved areas with high concentrations of low- and moderate-income families.

The Panel realizes that State agencies administering Title V may administer other State and Federal funds for services and activities affecting the health of women and children. In volume I of this Report, the Panel suggests that, to the extent practical, States organize all maternal and child health programs under a State Maternal and Child Health Authority that would work cooperatively with other governmental units to achieve national policy objectives in maternal and child health and mental health services and illness prevention.[16] However, the Panel believes that the Federal Title V appropriation and the required State matching funds should be used for the specific functions and services proposed here.

Planning Requirements

As part of the Federal planning requirements, the Title V legislation should require State Title V agencies to subdivide the State into regional service delivery areas that are compatible with, but not necessarily the same as, the health planning areas required by the National Health Planning and Resources Development Act. The State agency should be required to monitor the health status of children and pregnant women in each area, determine their needs for health services, including nutritional services, and assess the capability of existing resources to meet these needs. Based on this assessment, the agency should prepare a plan for developing new resources and upgrading and expanding existing ones.

The plan should identify the strategies—including advocacy, coordination, quality assurance, technical assistance, training, and direct funding—that will be used to implement the plan, and should specify the timetable for achieving each objective. A State might determine, for example, that in a particular service area there was a need to expand Title V health

[15] In the Panel's view, a comprehensive service should be defined in the statute as one that provides patients, at a single site or through formal linkages with another level of care, all preventive, primary, and specialized services.

[16] See volume I, chapter 10, of the Panel's report for a full discussion of the proposal for State Maternal and Child Health Authorities.

department services from well-child conferences into pediatric ambulatory services providing comprehensive primary care. This objective might be achieved in 18 months, during which the State agency staff would provide assistance in preparing the Title V grant application, make the grant award, and continue to provide the management and program assistance needed to complete the conversion. Or a State agency might determine that adequate services would be available if a specific facility improved the quality of its service, and that this objective could be achieved through monitoring, technical assistance, and training over the course of 9 months.

In carrying out these planning functions, the State agency should be mandated to give special attention to the needs of women and children for the four priority services identified by the Panel. Indeed, the statute should require that State agencies specify how these services will be made available throughout the State.

Because of the importance of developing maternal and child health resources that will improve the effectiveness of other Federal programs, the Panel recommends that States be required by statute to include in their plan specific information about the coordination of maternal and child health services with other related programs. States should be required, for example, to identify how specialized services for handicapped children will be coordinated with the implementation of P.L. 94–142, how preventive and treatment services funded or planned by the State Title V agency will be coordinated with EPSDT, and how each of these services will be made available to children in Head Start. States also should be required to describe joint efforts with the Developmental Disabilities Program and the Supplemental Security Income program of services to disabled children. Moreover, the Panel recommends that the Title V agency be directed to assume responsibility for developing the WIC service plan, provided it meets the affirmative action and other requirements prescribed by Congress and the Department of Agriculture.[17] All such planning must be carried out with the involvement of the State agencies or Federal regional offices responsible for administering these programs. Each agency would have to review and approve relevant components of the Title V plan.

It is imperative that this plan be consistent with the generic State Health Plan submitted to the Secretary under the requirements of the National Health Planning and Resources Development Act. Although the Title V plan would contain detailed information on maternal and child health services, strategies for change, and other issues specific to Title V, it would also contain certain information, such as health indicators and service needs, that must comport with the comprehensive health plan for the State. For this reason, the Panel strongly recommends that the Title V legislation require State Title V agencies to coordinate and cooperate with the State and local agencies—the State Health Coordinating Council (SHCC), the State Health Planning and Developmental Agency (SHPDA) and the Health Systems Agencies (HSAs)—responsible for developing the State health plan. The Panel also recommends that the Health Planning

[17]The Panel recommends, in its discussion on WIC in chapter 4 of this volume, that USDA require State agencies administering the WIC program to adopt this plan.

Act be amended to expand the present requirements for maternal and child health care services and to add explicit language requiring a joint effort with the State Title V agencies.

The process used to prepare these planning documents probably will vary from State to State. The Panel expects, however, that the SHPDA's appropriate responsibility would be to compile demographic data and information on available maternal and child health resources. Title V agencies, because of their clinical and program expertise, would be responsible for assessing the adequacy of existing resources and judging the need for new and improved services. Regardless of the exact division of responsibility, it is essential that State and local Title V agencies present their views to the SHPDA and HSAs through testimony, in public meetings and, informally, through routine staff communications.

Requirements for Promoting Quality and Accessibility of Services

The statutory requirements placed on the States for promoting the availability, accessibility, and quality of maternal and child health care throughout the State should include advocacy, technical assistance and training, quality assurance, coordination, and similar activities. The statute should require these activities to be broadly focused and to involve other publicly supported programs serving the health needs of children and pregnant women, including comprehensive health care centers, other primary care centers, family planning clinics, and inpatient and outpatient hospital departments.

The Panel envisions that State agency activities to improve the availability and quality of the maternal and child health care system might include, for example:

- persuading providers to supplement the services they now offer to include family planning or other needed services
- assisting appropriate local agencies in preparing a grant application for Title V or other funds
- providing training on prenatal risk screening to health department clinics, CHCs, and other programs serving pregnant women
- fostering the development of citizen advocacy groups for improved maternal and child health care
- establishing standards and monitoring mechanisms for Title V and other services, such as the medical and health services required as "related services" under P.L. 94–142

State agencies will not always be able to carry out these mandates directly. Bureaucratic constraints, insufficient resources, or lack of expertise may present obstacles, particularly in the area of advocacy. Legislation should, therefore, require States to achieve their objectives, when necessary, through contractual arrangements with appropriate public or private nonprofit organizations in the State.

Requirements for Service Programs

The other major function of State Title V agencies is the funding of MCH service programs. The Panel has several proposals it believes will result in better use of resources and increased program accountability.

The Panel recommends that the Title V statute specify that grant awards be made in each service delivery area in accordance with the objectives specified in the State Title V plan. The priority services—prenatal care, care for young children, care for handicapped and chronically ill children, and family planning—should be funded first. Meeting these priorities requires a service system comprised both of community-based primary care programs and regionalized programs in perinatal care, and secondary and tertiary care for specified handicapping and chronic conditions.

Grant funds should be used primarily to expand existing MCH programs and to establish new ones in order to build a coordinated system of comprehensive, high-quality health services for children and pregnant women, especially in medically underserved areas that have a high concentration of low- and moderate-income families. Any agency that can provide the services needed in its service delivery area and that meets all Federal and State provider standards should be eligible for grant funds. Standards prescribed by Federal statute should require that providers:

- meet all minimum service and quality standards for level and type of care prescribed by Federal and State regulation
- provide patients, at a single site or through linkages with other levels of care, all preventive, primary, and specialized services
- provide a comprehensive child health assessment and comprehensive health assessment for pregnant women, as appropriate
- provide outreach and followup services
- assure access to care through reasonable operating hours, provision for transportation and child care services, and other appropriate policies and mechanisms
- have cooperative arrangements with other sources of health care, including, as appropriate, pediatricians, obstetricians, hospitals, local WIC sponsors, federally funded clinics, Community Mental Health Centers, and social service agencies
- have cooperative arrangements with Head Start and day care projects, schools, family planning clinics, and other sources of referral
- undertake responsibility, as appropriate, in conjunction with local educational agencies for child-find activities and for diagnostic, evaluation, and health services required under P.L. 94–142
- establish internal procedures to assure program accountability, quality, and appropriateness of services
- maintain current health records for all patients
- make maximum use of new health professionals, such as nurse practitioners and physician assistants, and employ members of the community in appropriate positions
- develop and use an advisory board with a majority of consumers, at least half of whom must be users of the program

The statute should direct States to establish additional service requirements for the identification and treatment of certain types of illnesses, conditions, or disorders prevalent throughout the State or in a particular service delivery area. For example, a State with lead mines in certain service areas might require Title V providers to test all children receiving

services there for lead poisoning. Another State might have an influx of Southeast Asian refugees and determine that each immigrant child should be given appropriate tests for tuberculosis.

Title V legislation should provide that grants be awarded competitively. State agencies should carefully define needed services and the funding available to support them. Proposals then should be solicited from all qualified providers. Consistent with its conviction that many types of provider resources can and should be involved in the delivery of maternal and child health care, the Panel expects that eligible providers would include hospital ambulatory care centers, federally funded primary care centers, HMOs, and group practices of private physicians, in addition to local health departments and the MIC and C&Y centers. Grants should be made to the local or regional health provider that meets the provider standards and can best provide and make accessible a particular type or level of service required by the plan.

To minimize disruption in services, however, the Panel recommends that for the first 3 years the law is in effect, State Title V agencies should have the option of giving special preference to health departments and other current recipients of Title V funds. During that time, the State Title V agency should help these programs meet provider requirements and conform with the Title V plan. After the 3-year grace period, any recipient of Title V funds which did not satisfy all requirements could lose Title V support to a more qualified provider. If, however, there were no qualified alternative provider, the current recipient could continue to receive Title V funds so that women and children would not be cut off from services. However, the State agency would monitor such providers closely and continue to give technical assistance aimed at bringing about necessary program improvements.

The Panel recommends also that the statute set out requirements pertaining to the use of grant funds, limiting allowable costs to: reasonable administrative expenses, the cost of care provided to individuals not covered by Title XIX or private insurers, and the cost of certain services—including outreach and health education—which are not reimbursed under Title XIX or private insurance. As needed, "start-up" costs associated with developing a new program or resource should also be covered.

To assure that maternal and child health resources are available to as many as possible who require them, the Panel recommends that States be permitted to establish cost-sharing requirements for patients, provided that they are charged in accordance with their ability to pay. Services must be provided free of charge, however, to patients whose income, after adjusting for family medical and health-related expenses, is at or below a State-established rate set between 125 and 195 percent of the federally defined poverty level.[18] Additionally, no patient should be charged for diagnostic or preventive services.

[18]The Panel is suggesting the same range for the income eligibility standard required under the WIC program. See chapter 4 of this volume.

Additional State Requirements

The Panel proposes several additional legislative provisions relating to the overall administration of State Title V agencies. The Panel recommends, for example, that not more than 25 percent of a State's allotment be expended on administrative, planning, and advocacy activities; the remainder should be used for service project grants. The Panel recommends also that Title V agencies be mandated to have a full-time staff who meet all the qualifications and requirements prescribed by the regulation. The Panel expects that Title V agencies will be organized according to broad functions, such as planning, quality assurance, and service delivery, but that within service delivery there will continue to be one unit with special responsibility for maternal and child health services and another with responsibility for specialized health services to handicapped children.[19]

Another is that State Title V agencies be mandated to establish an appeals process for service programs that are disapproved for funding, or judged not to satisfy quality assurance standards. The process should provide for a State-level appeal, and then an appeal to the Federal regional offices.

To provide assistance and oversight to the State Title V agency and to advocate the health needs of mothers and children within State governments, the Panel recommends further that each State be required by legislation to create a Maternal and Child Health Advisory Council appointed by the governor. The majority of the council members should be knowledgeable citizens (not health professionals),[20] at least half of whom must be users of Title V and other publicly supported MCH programs. Other Council members should be members of various professions providing maternal and child health care, especially primary care, as well as planners and administrators of maternal and child health services. This Council must have responsibility for making recommendations to the governor and State Legislature on all State policies affecting the quality and accessibility of maternal and child health services, and to the State Title V agency director on the State Title V plan, the plan for service program grant awards, and all matters of general agency policy.[21]

The Panel recommends the statute specify that to receive Federal funding, State Title V agencies must submit a 3-year plan. The plan should contain all needs assessment, health status and other data, and information required by the Federal agency, and should specify performance objectives for each year and the strategies to achieve them. It should also contain information on staffing, State monitoring, and other administrative efforts.

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[19]The Panel is proposing that the term "Crippled Children's Services" be replaced by a term such as "specialized services for handicapped children" because it is more in keeping with the wide range of services today's Title V programs provide.

[20]Two Panel members dissented from this recommendation. See appendix C of this volume.

[21]See volume I, chapter 10, for a full discussion of the Panel's recommendations concerning the purpose and role of the proposed State Advisory Councils.

Finally, the Panel urges that the revised Title V statute contain penalties for States that are in substantial noncompliance with Federal requirements or that consistently are unable to meet reasonable performance standards. In such cases, the Federal administering agency should be authorized to withhold from the State agency all or part of its Federal Title V allocation. It should make arrangements for these funds to be administered temporarily by the Federal agency Director, another State agency, or a private nonprofit organization, so that individuals served by Title V programs in the State would not be penalized. Due process protections—including written notice, an opportunity for a hearing, and the right to reconsideration after a 90 day period—should be made available to the States.

Bureau of Maternal and Child Health Services

Legislative Authority

The legislation should provide that the Title V program be federally administered by a Bureau of Maternal and Child Health Services (BMCHS) within an appropriate agency of the Public Health Service.[22] As discussed in volume I, the Panel recommends that the Secretary of DHHS establish a Maternal and Child Health Administration (MCHA) to promote the coordination of all health care services to children and pregnant women.[23] If this Administration is created, the Bureau should be housed within it.

The statute should enumerate the duties of the Director of the BMCHS, including responsibility for administering Title V, promulgating regulations for its implementation, and ensuring full compliance with Federal requirements; carrying out a Federal discretionary grant program of research, training, and demonstration projects; and advocating Federal policies to improve the delivery of maternal and child health services generally. In addition, the Director should be required to review and approve regulations for the Title XIX EPSDT program and to participate in the development and implementation of policies and regulations for other departmental programs affecting the health of children and pregnant women.

The legislation should provide that a discretionary grant program plan be developed by the Director and approved by the proposed National Maternal and Child Health Commission.[24] Public and private nonprofit agencies and institutions should be allowed to compete for these funds with applications reviewed in an open and fair manner, using a peer review committee to evaluate proposals and recommend funding to the Title V Program administrator.

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[22]One Panel member dissented from this recommendation. See appendix C of this volume.

[23]See volume I, chapter 11, for a full discussion of the structure and purpose of the proposed MCHA.

[24]The Panel's legislative proposal for the National Maternal and Child Health Commission is discussed later in this chapter.

The law should specify that research grants be used to fund projects that will contribute new knowledge about effective clinical interventions and improved organization of maternal and child health services. Training grants should be used for degree and other training programs that will assure an adequate supply of national experts in maternal and child health policy, as well as administrative and clinical staff in the maternal and child health field, with special emphasis on developing staff from communities receiving Title V services. Training grants also should be used for conferences and programs to familiarize administrators, providers, and interested citizens with obstacles and solutions to establishing comprehensive maternal and child health service systems. Demonstration project grants should be used to fund projects that test innovative approaches to service delivery, or that promote effective methods of advocacy.

In order for the Bureau to carry out its broad mandate, the Panel recommends that the Title V legislation require the Bureau to have a central and regional office staff with sufficient capacity and administrative, planning, and clinical expertise.

Service and Provider Standards

One of the Bureau's primary responsibilities will be the prompt issuance of regulations and guidelines to implement the new legislative policies. Minimum service requirements for certain levels and types of services, such as preventive services for children, care for women with high-risk pregnancies, and specialized services to handicapped children, must be set by regulation. These should specify the components of each level or type of service, as well as national standards for personnel, facilities, and delivery of care. The Panel believes the standard-setting procedure should be a public process, and should continue to be undertaken in collaboration with the relevant professional and institutional groups, such as the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the American Nurses' Association, the American Medical Association, and the National Medical Association. It should also involve participation by other Federal programs administering MCH service programs and by child health advocacy groups.

The regulations should include a waiver policy for all federally established standards to cover limited instances where there is adequate justification for making an exception, such as the inability to obtain personnel with certain credentials in isolated areas. Federal regulations should also prescribe minimum expectations for monitoring performance: for example, how often records should be reviewed, who should conduct the audit, how large a sample is required, and when procedures other than record reviews are essential. The final standards and procedures should be reviewed and approved by the proposed Maternal and Child Health Commission. Each State Title V agency should have the option of setting higher standards for the programs within its boundaries, with the approval of its State Maternal and Child Health Council.

State Plan and Other Requirements

The regulations also should set out requirements for the contents of an approved State plan. These should include a full description of the State's maternal and child health objectives, timetables, and strategies. The plan should provide basic information regarding the designated service delivery areas, needs assessment method and findings, and procedures and criteria used to set priorities. In addition, service and provider standards, and all other programmatic, administrative, and budgetary information needed to assure compliance with Title V should be included. As part of these requirements, the Panel believes the Director may find it necessary, for example, to require States to outline their strategy for reducing mental retardation and infant and maternal mortality.

Furthermore, the regulations should establish data collection and reporting requirements for State agencies. In particular, the Panel recommends that State agencies collect three types of data, each of which can be analyzed and presented in different ways to meet different policy needs including accountability to BMCHS and internal agency management, as well as planning, quality assurance, and other State activities. These data are:

- *Management information* on receipt of services and use of funds, including the number and types of individuals served, services provided, provider characteristics, and Title V expenditures.
- *Service program evaluation data,* including data pertaining to services provided, populations served, and expected health outcomes measured against specific goals and objectives, as well as periodic and systematic on-site evaluations.
- *Policy-related epidemiological data* on health status and health care access, including problem-specific record reviews, such as studies of the antecedents of infant mortality based on linking birth and death records, or of the geographic distribution of women who receive inadequate prenatal care, or schools with low immunization rates.

The most important requirement is that the Bureau design a practical reporting system that will allow it to assess program performance and to manage Title V funds more effectively. One component is needed to collect and analyze data on the use of Title V funds by States. Examination of the budgets of several of the current State Title V programs should suggest categories of expenditures, such as planning or service program funding, that all States could be required to use. Another component is needed to determine who receives what services and from whom.

The Panel recommends that an expert committee be assembled to determine basic data needs and to establish a single comprehensive reporting system for the State Title V agencies. This system should be consistent and compatible with other relevant reporting systems, such as those for the EPSDT, Family Planning, and WIC programs. In addition, it should provide for tracking changes in the health status of children and pregnant women served under Title V. The committee should meet annually to examine aggregated State data, determine its validity and

usefulness, and make any necessary modifications in the collection system.

Coordination of Federal Activities

To assure that efforts and policies of the Bureau are coordinated with those of other Federal agencies concerned with the health care of mothers and children, the Panel recommends that interagency agreements be developed. In particular, since many of the other publicly sponsored programs such as the Community Health Centers are already involved in quality assurance through their funding agencies, the BMCHS should develop agreements with these agencies so that the same standards for care of women and children are instituted by both groups.

In addition to working with PHS's Bureau of Health Planning in devising regulations for the maternal and child health component of the State Health Plan, the BMCHS should issue guidelines to State Title V agencies, SHPDAs, SHCCs, and HSAs to assist them in understanding the implications for women and children of decisions made on Certificate-of-Need (CON) applications, Proposed Use of Federal Fund (PUFF) reviews, and Appropriateness Reviews. Even when the project or facility under review is not specifically designated for use by children and pregnant women, HSAs should consider the possible impact on maternal and child health care.

Monitoring and Technical Assistance

Finally, the Panel wishes to stress the importance of developing competence in program monitoring and technical assistance in the Federal Title V office and particularly in DHHS's 10 regional offices.[25] To carry out their new mandates for planning and promoting a high-quality comprehensive service system for women and children, State Title V agencies will need considerable guidance and support, and also will require close monitoring. In technical assistance, for example, regional offices should conduct workshops to explain Federal minimum service and provider standards and to teach methods of monitoring quality. They also should hold workshops on planning requirements and skills. On-site assistance in both areas should be provided as well. In monitoring, BMCHS staff should take an aggressive stance in determining if State agencies are meeting approved quality assurance and service provider objectives and fulfilling all other related Federal requirements.

Funding and Formula Changes

To achieve the purposes of this new Title V Program, both Federal and State administering agencies will require a substantial increase in Federal funding. The Panel recommends that Congress appropriate at least $800

[25]For a complete discussion of the Panel's recommendations concerning the role of the DHHS regional offices, see volume I, chapter 11 of this report.

million per year, just over twice the amount currently appropriated. This funding increase, along with other recommendations, will enable Title V agencies to bring essential maternal and child health services to women and children now classified as "medically underserved." It will also make available health services that will increase the effectiveness of many other federally supported programs, including WIC, P.L. 94–142, Head Start, Medicaid, and EPSDT.

Moreover, because of the priority that would be given to primary care, additional funding would, in the long run, show a positive cost-benefit ratio. Prenatal and family planning services reduce the costs associated with the delivery and care of premature and low-birth-weight infants. Comprehensive care for all children through age 5 reduces costly emergency room usage and hospitalization. In addition, improved services for handicapped children should reduce dependency, and augmented programs of prevention should reduce illness and injury, so that there would be cost savings in these areas as well.

Assuming the recommended increase in appropriations is adopted, the Panel believes that Congress must revise and simplify the formulas for apportioning Federal funds between State and Federal activities and distributing them among the States. The Panel recommends that up to 20 percent of the total appropriation should be retained by the Director of the Bureau of Maternal and Child Health Services to use at his or her discretion to support training, research, and demonstration projects.[26] The remainder should be allocated among the States by using a formula that gives each State a basic grant plus an amount reflecting relative need among the States.[27] Relative need could be established by using the combination of infant mortality and morbidity rates and adjusted *per capita* income.[26] The Panel suggests that Congress request a separate committee, perhaps the National Maternal and Child Health Commission proposed by the Panel, to make specific recommendations regarding this and other aspects of the formula.

The philosophy behind the Panel's financing recommendation for Title V is that States must be given an adequate budget, based largely upon need, and that they must be permitted flexibility in expending funds. For this reason, the Panel urges that the current practice of designating funds for MCH and CC purposes be discontinued, and that States receive their Federal allocation in the form of a single grant.[26] States should be required, however, to provide a cash match for the Federal Title V grant of an amount at least equal to 30 percent of the total, and to provide assurances that current matching levels will be maintained. In the third quarter of each fiscal year, any State that has not committed any portion of its Federal funds should be required to return those funds to the Bureau Director so that they may be awarded, with no match requirement, to a program in the State that is able to provide a service identified in the State plan.

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[26]One Panel member dissented from this recommendation. See appendix C of this volume.

[27]This formula would eliminate the authorization of funds under Section 516. However, because of the substantial increase in the total appropriation, the Panel believes that no State would be awarded less funding than it currently receives.

National Maternal and Child Health Commission

Finally, the Panel recommends that Title V legislation be the vehicle for establishing a congressionally mandated National Commission on Maternal and Child Health charged with serving as an advocate for the health needs of children and pregnant women. The Commission's duties should include:

- reporting every 3 years to Congress, the DHHS Secretary, the Assistant Secretary for Health, and the HCFA Administrator on the health status and service needs of children and pregnant women, and recommending Federal policy changes aimed at improving the efficiency and effectiveness of programs affecting the delivery and financing of these services
- reporting periodically to Congress, the DHHS Secretary, the Assistant Secretary for Health, the HCFA Administrator, and other Federal agency Directors, as appropriate, on Federal research and training activities affecting the quality and availability of maternal and child health services, and on regulatory activities related to substance and environmental risks to the health of children and pregnant women
- conducting studies and issuing reports to the public on the health needs of children and pregnant women[28]

To assure that sufficient guidance will be provided on the implementation of the new Title V requirements, Congress should direct the Commission to establish a committee with special responsibility for the Title V Program. This committee should be responsible for reviewing and approving the research, training, and demonstration project plans for Title V, and making recommendations to the Director of BMCHS on policy matters relating to the general administration of the Title V Program.

The Commission should be comprised of practitioners in pediatrics, obstetrics, nursing, and other health professions engaged in providing primary care to children and pregnant women; planners, researchers, and administrators in the maternal and child health field; and knowledgeable citizens, at least half of whom must be users of Title V and other publicly supported health care services. Members should be appointed by the Secretary of DHHS for terms not to exceed 3 years, with one-third of the membership rotating annually. Staff and financial support should be provided from the budget of the Secretary.

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[28] See volume I, chapter 11, for a complete discussion of the responsibilities that might be assigned to the proposed National Commission.

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CHAPTER 3

MEDICAID AND EPSDT

MAJOR RECOMMENDATIONS

- Mandate eligibility for all children and pregnant women whose family income is at or below the federally established poverty level, including children living in two-parent families, and first-time-pregnant women.
- Require coverage of all essential services for children and pregnant women, including appropriate obstetric, dental, mental health, and clinic services.
- Require that certification for participation in Medicaid be extended to all qualified comprehensive care providers meeting prescribed requirements, and that reimbursement levels be sufficient to assure adequate provider participation in the Medicaid program.
- Establish policies to improve the State administration of Medicaid and its EPSDT program, especially the outreach, referral, and followup components.
- Require the establishment of minimum acceptable standards for screening and other preventive services, and for participating providers.
- Increase Federal financial participation in Medicaid and establish financial incentives for States to achieve Federal objectives in maternal and child health care.

PROGRAM DESCRIPTION AND ACCOMPLISHMENTS

The Medicaid program, legislated by Title XIX of the Social Security Act,[1] was created by Congress in 1965 to ensure financial access to health care for the poor. Built upon the welfare model, Medicaid is constructed as a State-administered medical assistance program to reimburse providers for health care delivered to beneficiaries. Participation is based upon entitlement, and Federal grants match State expenditures for the costs of administration, medical services, and special services such as outreach and

[1] Title 42 U.S.C. Sect. 1396 *et seq.* (1976 & Supp. II 1978).

transportation. Statutorily mandated program requirements are minimal: the law permits States wide latitude in determining eligibility, covered services, and provider standards.

Among the basic requirements specified in the legislation are those pertaining to eligibility. States participating in Medicaid are required to cover persons who are "categorically needy": all residents receiving public assistance under Aid to Families with Dependent Children (AFDC), and most receiving assistance under Supplemental Security Income (SSI) for the aged, blind, and disabled. At State option, categorical coverage may be extended to financially eligible pregnant women, and to families in which the father is unemployed, if these groups are not covered in the State's AFDC plan. Categorical coverage may also be extended to children of two-parent families which meet the AFDC income standard (the so-called "Ribicoff children"). However, States are permitted by regulation to limit coverage for such children to certain "reasonable" subgroups, such as those in foster care or psychiatric hospitals.

In addition, States are permitted to provide Medicaid benefits to the "medically needy." These are individuals whose family income exceeds the State's income eligibility standard, but who meet the AFDC or SSI categorical criteria and are unable to pay all or part of their medical expenses. Children from two-parent families may be included as well. Financial eligibility for the medically needy program may be set at an amount up to 133 percent of the State's AFDC payment level. As interpreted by the regulations, individuals may, depending upon their income or medical expenses, be required to "spend down" to the AFDC eligibility level in order to receive Medicaid benefits.

The statute also specifies minimum benefit requirements. For categorically eligible recipients and the optional groups subsumed under the categorical program, the law mandates coverage of certain basic services, including hospital, physician, laboratory and X-ray services, family planning, and, for persons under 21, early and periodic screening, diagnosis, and treatment services. Other services, such as clinic services, prescription drugs, and physical therapy, may be provided at State option. For medically needy recipients, the State may either provide the mandatory service package or develop a different package consisting of at least seven of any federally reimbursable services.

Regardless of whether a service is mandatory or optional, however, the State is free by statute and regulation to limit the amount, duration, and scope of coverage.[2] In addition, the State may establish "nominal" cost-sharing requirements for any optional service to the categorically eligible and for all services to the medically needy.

The requirement that States provide early and periodic screening, diagnosis, and treatment (EPSDT) as a mandatory Medicaid service was established by the 1967 Title XIX Amendments, which were part of a larger package of broad-ranging amendments to the Social Security Act programs. Congress had become convinced that improving the health status of children from low-income families would require preventive

[2]The only qualification of this policy is the regulatory requirement that coverage of a service must be "sufficient to reasonably achieve its purpose." (Title 42 C.F.R. Sect. 440.230 & 1979).

health services typically not available under the existing Medicaid program.

The legislative directive was vague, however, and the design as well as the implementation of EPSDT was left to the Department of Health, Education, and Welfare (DHEW).[3] Agency regulations prescribed that, in addition to the services covered by a State's Medicaid plan, EPSDT treatment services must include certain types of visual, hearing, and dental care. Also required is a specific screening package that must be available to all eligible children in accordance with the State-established schedule for periodic rescreening.

New functional responsibilities mandated by DHEW further distinguish EPSDT from the general Medicaid program. Whereas Medicaid operates primarily as a vendor payment program for medical services, EPSDT regulations require States to provide or purchase the care and services necessary for identifying eligible children, informing them of the EPSDT program, and assuring that needed preventive and curative services are provided. To meet these requirements, States are authorized to contract with local organizations to provide required medical or support services, enter into EPSDT provider agreements, and set separate reimbursement rates for a required set of screening and diagnostic services.

In 1972, Congress, concerned over the States' sluggish implementation of EPSDT, amended Title IV–A of the Social Security Act to include a penalty provision that would reduce a State's AFDC grant by 1 percent for each quarter in which it was not in compliance with certain EPSDT requirements. The law specifies that this sanction is to be imposed against any State that fails to inform all AFDC recipients about EPSDT, provide and arrange for screening when requested, and arrange for necessary corrective treatment. Regulations base compliance on measurable outcome criteria, such as the percentage of children for whom screening and initial treatment have been completed during a specified time period.

Federal administrative responsibility for the Medicaid Program rests with the Health Care Financing Administration (HCFA) within the Department of Health and Human Services (DHHS). Administration of EPSDT is the special responsibility of HCFA's Office of Child Health (OCH).

All States but Arizona operate a Medicaid program. In most States, the administering agency is either a health or welfare department, or an umbrella human services agency. To meet EPSDT requirements, however, a State Medicaid agency may assign responsibility for various functions, including outreach, screening, diagnosis, treatment, case management, and transportation, to other departments within the State government. These agencies, in turn, may subcontract with local organizations to provide the required services.

Medicaid is financed jointly by State and Federal funds, with the current Federal contribution to the cost of medical services ranging from 50 to 77.55 percent, depending on the average *per capita* income of State residents. In FY 1979, State and Federal Medicaid expenditures were just under $21.4 billion; the Federal share was $12.1 billion and the State share

[3] In April 1980, the Department of Health, Education, and Welfare was divided into two independent departments: the Department of Education and the Department of Health and Human Services.

was $9.3 billion. An estimated 2.14 million children were served by EPSDT that year.[4]

Prior to the enactment of the Medicaid legislation, there were some poor women and children who had access to limited clinic and other health care services supported by Federal, State, and local funds. Millions, however, depended upon the charity of public and private health providers for needed health and medical care. Many were able to obtain this care, but many others could not. For those eligible, the Medicaid program has substantially eliminated the financial barrier to the most costly health care services. Much evidence suggests that Medicaid has exerted a significant positive impact on the use of medical services by children from low-income families. In fact, in simple quantitative terms, poor children now use medical services about as often as do affluent children.[5]

Moreover, the establishment of EPSDT has meant that other impediments to appropriate care are now being addressed, with the result that many children who need medical services most are finally being brought into the health care system. EPSDT is demonstrating that aggressive preventive strategies—outreach, early diagnosis, and followup for treatment—are effective, and indeed essential, to improving the health of the Nation's poor children.

Meeting the objectives of EPSDT requires the marshaling of various health, mental health, social service, and other resources. Federal leadership is imperative, and the Department's recent efforts to design and implement a major "Child Health Strategy" are promoting improved coordination among all the programs having an impact upon child health. As part of this initiative, schools and school-based programs are being used to provide outreach and referral, Head Start children are moving toward full participation in EPSDT, and the Public Health Service (PHS) programs increasingly are obtaining reimbursement under Medicaid.

BASIS FOR RECOMMENDATIONS

Despite intensified Federal and State efforts to improve the administration of Medicaid and EPSDT, when these programs are judged by the extent to which they assure children and pregnant women access to appropriate health care the results are disappointing.

The failure of Medicaid and EPSDT to reach their full potential is largely attributable to the basic Federal statutory scheme under which they operate. The legislation allows States extensive autonomy in setting benefit, eligibility, and provider participation policies. It requires the strict

[4]This number includes only children receiving EPSDT assessment services within the year. DHHS estimates that including children with up-to-date assessments who did not require an assessment in that year would raise the total number of children reached by the program substantially.

Comparable figures for the number of children and pregnant women served by the general Medicaid program are not available, although Medicaid beneficiaries under age 21 received 10.7 million visits or services, the expenditures for which totaled approximately $4 billion.

[5]See, for example, Butler, J. A. and R. K. Scotch, "Medicaid and Children: Some Recent Lessons and Reasonable Next Steps." *Public Policy* 26: 6, and table 2, Winter 1978.

application of categorical and income standards in determining individual eligibility. And, perhaps most important, it relies on State financing initiative while offering little incentive for providing comprehensive service coverage or for assuring effective outreach and referral. In fact, States doing a good job are faced with the greatest marginal expenditures.

Of major concern to the Panel is the fact that Federal statutory policies governing Medicaid eligibility are inadequate to assure that in each State all children and pregnant women from low-income families can participate in Medicaid. Income eligibility standards vary considerably among States, ranging from a maximum annual income of $2,244 for a family of four in Texas to $6,600 for a family of four in Hawaii. Even accounting for differences in cost of living, the eligibility level in Hawaii is set at an income which is twice as high as in Texas.[6] As a result of these income policies, nationwide an estimated 7 million children with family incomes at or below the federally defined poverty level are excluded from receiving Medicaid benefits.[7]

In addition, many States choose not to extend coverage to optional groups. Only 31 States cover first time pregnant women, only 30 cover families in which the father is unemployed, and only 20 provide benefits to all children of two-parent families which meet the AFDC income standard. Only 33 States provide benefits to the medically needy, and a number of States—striving to contain rising Medicaid expenditures—are either reducing the income eligibility level for these benefits or not raising the level to keep pace with inflation. Many States also impose residency requirements that limit or exclude participation by migrant families. Moreover, certain categories of children, such as the children who are inmates of nonmedical public institutions, are outside the scope of the Medicaid legislation itself.

Even for children and pregnant women who do participate in the Medicaid program, continued eligibility is always precarious. The family structure may change or family income may increase. Loss of eligibility often means that necessary treatment services are disrupted. One report showed that in the course of a single year, no less than 35 percent of EPSDT children lost eligibility for Medicaid.[8]

The Panel is also concerned that current Medicaid policy does not assure coverage of essential health services for children and pregnant women. For example, many States restrict coverage for prenatal care to fewer than the 13 visits recommended as a minimum by the American College of Obstetricians and Gynecologists. Many also place arbitrary limits on the number of physician visits and outpatient hospital visits by children. In addition, the majority of States either do not cover the optional diagnostic and treatment services that may be indicated as a result of an EPSDT screening, or they limit coverage of these services to

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[6]Based on 1975 cost-of-living data from the Census Bureau, Household Income Division.

[7]Medicaid-Medicare Management Institute (MMMI). *Data on the Medicaid Program: Eligibility, Services, Expenditures.* Publication Number HCFA 79-20005, Baltimore, Md.: DHEW, Health Care Financing Administration, 1979 (Revised).

[8]Children's Defense Fund. *EPSDT: Does It Spell Health Care for Poor Children?* Washington, D.C.: Washington Research Project, Inc., 1977, p. 31.

less than is needed. This is especially true for physical, speech, and occupational therapy, prescription drugs, prosthetic devices, and mental health treatment services. The bias against reimbursing for outpatient psychiatric care is particularly strong.

A serious problem for handicapped children is that some States disallow Medicaid reimbursement for health services that are provided as part of an Individualized Education Program (IEP) required by the Education for All Handicapped Children Act, P.L. 94–142, even though the services are included in the State's Medicaid Plan and delivered by a certified provider to a Medicaid-eligible child. In these States, handicapped children actually are losing entitlement to Medicaid-covered services as States shift fiscal responsibility from one agency to another.[9]

Another aspect of inadequate service coverage is patient cost sharing, operative in many States. As permitted by statute, 15 States require deductibles, coinsurance, or copayments for optional services to the categorically needy or for all services to the medically needy. Evidence available to the Panel strongly suggests that these policies present an economic barrier to care for the poorest participants. At the same time, they increase administrative costs substantially and generally do not reduce inappropriate service utilization.[10]

The shortage of participating providers, especially of those able to assure the comprehensiveness and continuity of care that the Panel believes is essential, also limits access to appropriate health care. Private physicians, particularly obstetricians and family practitioners, often refuse to accept Medicaid patients because of extensive paperwork, delayed payment, racial and class prejudice, and particularly because of low reimbursement. As has been well documented, Medicaid usually reimburses private physicians at a rate below that provided by private insurers.[11]

Medicaid reimbursement policies pose special problems for health maintenance organizations (HMOs) and for clinics, including hospital outpatient departments, Community Health Centers, maternal and infant care projects, public health departments, and crippled children's service programs. Most States have not established capitation reimbursement for health maintenance organizations and many do not provide coverage for clinic services. As a result, they often exclude important providers of comprehensive care. Further, if HMOs and clinics are reimbursed for fee-for-service physician care, they usually receive an amount considerably below their cost.

Care rendered by nonphysician personnel, such as nurse practitioners and nurse midwives, is not covered at all in most States, even when it is provided in a clinic or HMO setting. Reimbursement for psychiatric social workers and clinical psychologists providing mental health treatment

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[9] As discussed in chapter 5 of this volume, insufficient funding under P.L. 94–142 makes it impossible for local education agencies to absorb the total cost of health and other educationally related services.

[10] Rosner, M. "Co-payments for Ambulatory Care: Penny-Wise and Pound-Foolish," *Medical Care* 13: 457, June 1975.

[11] Comptroller General of the United States, General Accounting Office. *Better Management and More Resources Needed to Strengthen Federal Efforts to Improve Pregnancy Outcome: Report to Congress.* Washington, D.C.: U.S. Government Printing Office, 1980.

services in a Community Mental Health Center or other organized care setting is even rarer. The effect of these policies is to force health care institutions either to forego Medicaid payment for these services, or to obtain payment by billing for reimbursement as a physician visit.

The Panel believes that in addition to the restrictive eligibility, benefit, and provider reimbursement policies adopted by the States, insufficient administrative capacity has limited the success of Medicaid and especially the EPSDT program. State Medicaid agencies generally received EPSDT with confusion and even disinterest. Many were inexperienced in assuring the availability and quality of health care services, and most were totally unaccustomed to seeking out beneficiaries and assisting them in arranging for the delivery of services.

In many cases, State agencies have not done enough to overcome these initial administrative problems and have not adequately assumed responsibility for assuring that the goals of the EPSDT program are achieved. Nationally, only a small percentage of the children eligible for EPSDT have been screened because most States have not been aggressive in providing outreach, especially community-based outreach and other methods known to be effective. Also, a large number of the screenings that children do receive are incomplete, primarily because most States have failed to ensure that even the required screening package is provided. In addition, many of the medical problems identified through screening procedures are not treated because States have failed to provide the necessary followup.[12]

State administering agencies generally have not taken measures to assure the availability and appropriateness of EPSDT providers. Community health centers and other comprehensive care providers frequently are overlooked when States enter into EPSDT provider agreements. Moreover, several States use EPSDT providers, such as public health department clinics, which are not always effective in linking children with ongoing sources of primary care. States also have not assured that enough medical specialists to treat problems detected through screenings are participating in Medicaid.

The record of the Federal Government in administering EPSDT has also been poor. From the outset, program regulations have been slow to emerge from the Department. The first set of regulations to implement EPSDT was issued by DHEW in late 1971, after a 4-year delay,[13] and did not take effect until 1973. Although regulations establishing a mandatory screening package have been issued recently, Federal guidelines for assuring the quality of these services still are insufficient. The regulations require a hearing examination, for example, but provide no guidance regarding the scope of the examination.[14] Furthermore, until very recently,

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[12]Children's Defense Fund, *EPSDT: Does It Spell Health Care for Poor Children?* Washington, D.C.: Washington Research Project, Inc., 1977, p. 31.

[13]One factor which prompted the release of the regulations was the institution of a lawsuit, *National Welfare Rights Organization v. Richardson*, brought on behalf of Medicaid beneficiaries.

[14]The Panel does not mean to imply that the Federal Government should regulate medical practice, but rather that it should require that standards established by recognized authorities, such as the American Academy of Pediatrics, be met by providers receiving public funds for the provision of health care services.

Federal reporting requirements for the States were concerned primarily with the State expenditures for services, and were not designed to yield the most basic information about the populations served and the services rendered.[15]

PLAN OF ACTION

Based on its analysis of the current Medicaid program, the Panel calls for changes that it believes will establish a more equitable and effective health program for low-income children and pregnant women—one which will assure financial accessibility to high-quality, comprehensive care nationwide. The Panel recommends:

- setting eligibility standards at the federally established poverty level, without regard to family structure
- requiring coverage of all essential services
- bringing comprehensive health care providers into the program and guaranteeing them reasonable terms of participation
- establishing standards for preventive services and certified providers
- improving State administration of the program through fiscal incentives and other mechanisms

Implementing the Panel's recommendations will require major statutory revisions as well as modifications in regulatory policy and expansion of administrative efforts. At the time of this writing, many of the statutory proposals advocated by the Panel are contained in legislation before Congress.[16] Many of these proposals are similar to its own and, to the extent that they are, the Panel fully endorses them.

Creating Uniform Eligibility

Central to a new legislative basis for Medicaid are changes in the policies governing eligibility. The Panel concludes that Federal law must assure Medicaid eligibility to all children up to the age of 18 and to all pregnant women whose adjusted family income is at or below the federally established national poverty income standard.[17] In addition, since a significant number of States presently include individuals with family incomes above the poverty level in their medically needy programs, the law should prohibit States from eliminating or in any way reducing benefits to current Medicaid recipients. The law also should mandate eligibility for children who are inmates of public institutions, providing

[15]See, for example, Reis, J. *et al. An Assessment of the Validity of the Demonstration and Evaluation Program for the EPSDT Program: A Metaevaluation.* Evanston, Ill.: Northwestern University, Center for Health Services and Policy Research, 1979.

[16]U.S. Senate 1204, Child Health Assessment Act of 1979; U.S. House of Representatives 4962, Child Health Assurance Act of 1979.

[17]At the time of this writing, the national poverty level set by the Department of Commerce was $8,000 per year for a family of four.

they were eligible prior to entering the facility. To minimize disruption in care, eligibility for children and pregnant women should be retained for 1 year following a completed health assessment, regardless of changes in income.

The Panel recommends further that existing provisions which serve to restrict participation by current or potential beneficiaries be eliminated. States, for example, should no longer be able to impose intent of residency or other requirements that would effectively exclude individuals otherwise eligible for Medicaid from receiving benefits in any State.

Assuring Coverage for Essential Services

In order to assure coverage of all services essential to the health care of children and pregnant women, the Panel recommends that States be statutorily mandated to provide coverage for the following services in addition to those already required.

For Children:

- comprehensive child health assessments, including health history, general physical examination, developmental assessment, nutritional assessment, and all appropriate laboratory tests and X-rays
- immunizations
- diagnosis and treatment of vision and hearing problems
- routine dental care, including preventive, restorative, and emergency services and noncosmetic orthodontia
- prescription drugs, eyeglasses, hearing aids, and prosthetic devices
- physical, speech and occupational therapy
- mental health services, including outpatient therapy, day treatment, residential treatment, and emergency inpatient services
- residential treatment services for the mentally retarded
- clinic services

For Pregnant Women:

- comprehensive prenatal health assessments, including health history, physical examinations, appropriate laboratory tests, and screening and counseling for nutritional inadequacy, substance abuse, and other behavior patterns harmful to fetal development
- services to manage high-risk pregnancies
- regular prenatal examinations
- prescription drugs
- preventive, restorative, and emergency dental services
- mental health services, including outpatient therapy, day treatment, and emergency inpatient services
- pregnancy-related hospital admissions
- labor and delivery care and services
- clinic services
- postpartum examinations including, as appropriate and desired by the beneficiary, family planning services

Although several of these services—particularly the child health assessments, immunizations, and certain visual, hearing, and dental

services—are currently required by regulation, the Panel believes that coverage for the full component of essential preventive, diagnostic, and treatment services should be guaranteed and protected by congressional mandate.

The legislation should stipulate that these services, plus the currently required physician and hospital services, cannot be limited in amount, duration or scope, provided they are medically necessary. It also should prohibit the establishment of patient cost sharing requirements. To clarify the use of Medicaid funds as first dollar coverage, the legislation should specify that any Medicaid-covered health service provided to a handicapped child as part of an Individualized Education Program under P.L. 94–142 must be reimbursable.

Encouraging Provider Participation

The Panel also proposes legislative amendments to encourage participation of all appropriate health care providers, including several provisions which would place requirements on the States. First, the Panel urges that States be required to reimburse all qualified child health care providers who agree to perform comprehensive child health assessments, provide immunizations, and make all reasonable referral and followup arrangements to assure the provision of indicated diagnostic and treatment services. States also should be required to reimburse all qualified providers of comprehensive prenatal, maternity, and postnatal care. Among the kinds of providers that should be eligible to provide both types of services are private physicians, public health departments, Community Health Centers, HMOs, and hospital outpatient departments.

Second, the Panel recommends that States be required to reimburse all qualified providers of diagnostic and treatment services covered by Medicaid. Such providers should include, among others, Community Health Centers, Community Mental Health Centers, crippled children's clinics, and private medical and dental specialists.

Third, the Panel recommends that services provided by nurse practitioners, nurse midwives, physicians' assistants, medical and psychiatric social workers, clinical psychologists, and other qualified health professionals be reimbursed when delivered in an organized health or mental health care setting. The Panel has decided not to recommend that these services be reimbursed under a direct billing arrangement because it believes alternatives to fee-for-service reimbursement should be developed and is opposed, therefore, to any significant expansion of fee-for-service reimbursement.

Other recommendations for expanding provider participation would establish legislative directives to the Secretary of Health and Human Services. The Panel believes that Congress should require the Secretary to establish minimum allowable reimbursement rates for ambulatory care provided by individual practitioners and clinics. These rates should be sufficient to assure an adequate supply of ambulatory care providers to meet the needs of children and pregnant women and, as appropriate,

should be set at an amount not less than 80 percent of the Medicare rate for comparable services.[18]

In addition, financial incentives to promote continuity of care should be authorized by Congress and implemented by the Secretary. These should include reimbursement to cover referral, followup, and reporting costs incurred by participating providers. They also should include capitation payments for continuing care providers, that is, providers who agree to deliver basic primary and preventive care on an ongoing basis to specific children or pregnant women with their consent. Providers participating under this contractual arrangement should be required to be reasonably accessible to patients at all times and to assume responsibility for the management of the patient's comprehensive health and medical care needs, including the arrangement of all necessary diagnostic and treatment services.

Financing State Programs

Also recommended by the Panel are major revisions in the statutory provisions governing Federal financial participation. In essence, the Panel is advocating a restructuring of Federal matching requirements to encourage and reward improvements in State Medicaid programs.

The Panel proposes that the Federal matching rate for ambulatory services to all Medicaid-eligible children and pregnant women be increased by adding up to 25 percentage points to the States' current matching rate, up to a maximum of 90 percent, varied according to performance criteria to be set by regulation. Within these limits, greater weight should be given for children and pregnant women enrolled with a continuing care provider. In addition, the Federal matching rate for outreach services[19] should be increased to 75 percent. This rate should be provided to States regardless of whether the service is performed by a community-based, private nonprofit agency or by a public agency. What is important, the Panel believes, is that the agency involve low-income people, familiar with neighborhood institutions and networks, as outreach workers. Special training in the requirements of Medicaid and in the medical and health resources of the community is essential. However, supervision by skilled medical personnel is not always necessary, and should be eliminated as a legislative requirement for receiving the special Federal match for outreach services.

To receive these higher matching rates for any service—ambulatory, referral, or outreach—States should be required to maintain current financing levels and program requirements. Provision also should be made for States that do even better than the mandated reasonable performance

[18]The Panel recognizes that in many States Medicaid payment levels currently equal 80 percent of Medicare rates for comparable services, such as physician visits. In making this recommendation, the intent of the Panel is to assure that payment levels in *all* States meet a reasonable minimum standard.

[19]As used here, the term outreach refers to informing beneficiary families of the EPSDT program, encouraging their participation, and making necessary transportation and support services arrangements.

level. In such instances, increases in the Federal share of administrative costs, up to 25 percentage points, should be permitted.

Improving Program Administration

Finally, the Panel recommends that the Secretary be mandated to promulgate all regulations and pursue all administrative actions necessary to assure full implementation of this revised Medicaid program for children and pregnant women. In particular, the Panel proposes that the Secretary be directed to issue regulations addressing standard-setting, State plan requirements, and alternative approaches to fee-for-service reimbursement.

New Regulations

Regulations establishing standards for the Medicaid and EPSDT programs should specify the minimum package of preventive, diagnostic, and treatment services to which children and pregnant women are entitled. They should set out the appropriate scope or essential components of these services and should prescribe minimum Federal requirements for an acceptable periodicity schedule for the delivery of these services.

In order to promote consistent standards among the various Federal programs providing health services to children and pregnant women, the Panel believes it critical that these regulations be developed by HCFA in conjunction with other Federal agencies administering health programs for children and pregnant women, in particular the National Institute of Mental Health, the Federal agency administering WIC, and the Federal agency administering Title V.[20] HCFA currently is working with PHS to develop mutually acceptable periodicity requirements, but much additional collaboration is needed. Standards for the nutritional component of the child health assessment, for example, should be consistent with the WIC (the Special Supplemental Food Program for Women, Infants, and Children) nutritional risk assessment so that a single procedure would fulfill the requirements of both programs.

State Medicaid agencies should, in turn, be charged by these regulations with developing a more specific set of service standards responsive to State and local conditions. Like the federally established standards, State service standards should be developed in cooperation with other agencies administering MCH programs, particularly the State Title V, WIC, and mental health service agencies. Reimbursement mechanisms and other State policies should be established to assure that standards are met and are uniform among programs. All State Medicaid agencies should be required to develop monitoring plans and to identify appropriate State or local organizations to assume responsibility for their implementation.

[20] In volume I, chapter 11 of this report, the Panel recommends that the Secretary of DHHS establish a Maternal and Child Health Administration within the Public Health Service to administer some, and coordinate all, health programs for children and pregnant women. If established, it would be appropriate for this Administration to participate in the development of these standards.

Federal regulations concerning provider participation should follow a similar approach. They should set forth minimum requirements that a provider must meet in order to be certified as a general Medicaid provider, an EPSDT provider, or a continuing care provider. Such requirements should mandate, for example, that child health assessment providers have written agreements with providers of certain diagnostic and treatment services. Within this framework, States should be directed to develop more detailed provider standards, drawing upon the expertise of the appropriate State agencies and professional associations.

Additionally, of course, State performance standards or requirements should be prescribed by Federal regulation. These requirements should establish minimum performance levels in outreach, assessment, and treatment services to Medicaid-eligible children and pregnant women.

The State Medicaid plan, in the Panel's view, is a mechanism that can be used to effect significant program improvements. Regulatory policy prescribing the content of State plans must, therefore, be structured for this purpose. The Panel recommends that current regulatory requirements be expanded to specify that, as a condition of approval, each State Plan must contain:

- a description of provider availability in the State and a detailed strategy for overcoming shortages
- a specific strategy for bringing continuing care providers into the program
- a plan for providing outreach and eliminating obstacles to eligibility certification
- a strategy for resolving transportation, child care and other barriers to receiving needed services
- the service and provider standards adopted by the State
- a plan for monitoring and assuring the quality of care

State Medicaid plans should be reviewed critically by the Secretary and should not be approved unless they reflect adequate measures, in the Secretary's opinion, to achieve Federal Medicaid objectives. If a State plan is found to be deficient, members of the HCFA staff should enter into negotiations with the State agency to work jointly on the development and implementation of a more effective plan.

Regulations also should instruct State agencies to pursue prepayment contracts in addition to capitation payment for continuing care providers. Prepayment contracts should be used for the provision of EPSDT services where this type of financing ensures a more effective and efficient means of delivering a particular service. There are two types of situations in which prepayment for a health or medical service should be authorized. The first is where a discrete preventive service, which usually is not part of primary care provided in a physician's office, can be delivered quickly to large numbers of children at a single site. Preventive dental services, hearing examinations, and visual testing provided in the schools, for example, would meet these requirements. The second situation is when a provider agrees to accept a certain number of referrals over the course of a year or other specified time period. Under this type of arrangement, a therapist might provide group counseling sessions for emotionally disturbed teenagers, or an orthodontist might furnish braces to an agreed-

upon number of children. States should be required to consider both types of prepayment contracts as a means of both assuring accessibility to preventive and other essential services and of reducing service costs. The Panel believes that States will be able to pay less on a negotiated group rate than they would if providers were to bill for each patient on a fee-for-service basis.

Additionally, States should be directed to enter into prepayment contracts, whenever possible, for the delivery of outreach services. For this type of service the prepayment contract should operate much like a grant, and it might be appropriate for the State agency to issue a public request for proposals and also to solicit applications from specific community agencies already involved in successful outreach efforts.

Other Administrative Actions

Beyond promulgating regulations, the Panel believes that other steps are necessary to improve the administration of the Medicaid program. For one, the Panel recommends that HCFA undertake an active review and monitoring of State programs. Monitoring would be especially necessary to determine whether States were meeting new performance requirements and warranted the proposed increased Federal match. For another, the Panel suggests that demonstration project and research funds be used to develop knowledge about attracting and reimbursing continuing care providers, effective delivery of outreach, and appropriate followup and tracking systems.

Finally, the Panel believes there is need for a considerable expansion of technical assistance to the States, particularly concerning outreach, followup, provider participation, and data collection responsibilities. HCFA should, for example, move quickly to institute the new Medicaid reporting system. This system, known as the Quarterly Child Health Status Report, for the first time requires States to furnish information about Medicaid beneficiaries and the services they receive. States undoubtedly will require assistance in developing the management capability to meet these new requirements.

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CHAPTER 4

WIC: THE SPECIAL SUPPLEMENTAL FOOD PROGRAM FOR WOMEN, INFANTS, AND CHILDREN

MAJOR RECOMMENDATIONS

- Continue to increase congressional appropriations for the WIC program to enable more eligible women, infants, and children to receive WIC benefits.
- Establish planning, administrative, and service delivery requirements to assure the availability of WIC-required health services and to improve coordination between WIC and programs providing or financing maternal and child health services.
- Require States to set income and nutritional risk eligibility standards for the WIC program that will target WIC benefits to all infants, children, and pregnant, postpartum, and lactating women in financial and nutritional need.
- Implement outreach and other activities to increase access to WIC program benefits.
- Expand Federal and State monitoring and technical assistance efforts to ensure that the program is located in areas of greatest need and that WIC sponsors meet all food distribution and nutrition education requirements and provide access to needed health services.

PROGRAM DESCRIPTION AND ACCOMPLISHMENTS

In response to growing evidence linking nutritional inadequacy to mental and physical defects and increasing knowledge that proper nutrition contributes to better health, Congress, in 1972, enacted the Special Supplemental Food Program for Women, Infants, and Children[1]

[1]Title 42 U.S.C. Sect. 1786 (1976 & Supp. II 1978).

(known generally as the WIC program) as an amendment to the Child Nutrition Act of 1966. Under its present structure, WIC provides nutritious food and nutrition education to low-income pregnant, postpartum, and lactating women, infants, and children to the age of 5 who are determined to be at a special nutritional risk. Participation in other food programs does not preclude participation in WIC.[2]

The congressional purpose in enacting the WIC program was clearly both preventive and therapeutic. Unlike other supplemental food programs, WIC was designed to establish a new, special relationship between nutrition and health care services. The legislation states that the program is to "... serve as an adjunct to good health care, during critical times of growth and development...." In an attempt to accomplish this goal, Federal regulations mandate that local agencies may qualify as WIC sponsors only if they can make health care services available to WIC enrollees. These statutory and regulatory provisions make WIC the first food assistance program to tie eligibility to nutritional need and to require access to the provision of health care services.

Eligibility in the WIC program is based upon two criteria: nutritional risk and income. The statute defines "nutritional risk" to include four categories of people, ranging from those with documented nutritionally related medical conditions to individuals with dietary deficiencies that impair or endanger health. The determination of an applicant's nutritional status must be made by a physician or other competent professional authority. The law states that the income requirement can be fulfilled only by persons who meet the income standards prescribed for free and reduced-price school meals under the National School Lunch Act. Once an applicant has been accepted into the program, periodic recertification is required to assure that he or she continues to meet both the nutrition and income eligibility criteria.

The WIC program consists of two services provided to participants at no cost. The first, of course, is food distribution. The Department of Agriculture (USDA) has authorized several food packages, each of which must be prescribed under professional guidance to reflect individual nutritional needs. Food packages are made available to participants through vouchers, by direct distribution, or by home delivery. The program's second service is nutrition education. Federal regulations require that nutrition education activities emphasize the relationship between proper nutrition and good health, and assist WIC participants to achieve positive changes in their eating habits. In addition, the regulations specify that State agencies must employ at least one professionally trained nutritionist or dietician to be responsible for planning and implementing nutrition education activities throughout the State, and for ensuring that local agencies properly carry out the program's nutrition education service.

WIC also provides access to health services for its participants. As defined by Federal regulations, these services include ongoing, routine

[2]The sole exception is the Commodity Supplemental Food program. Because the two programs are identical except for their food delivery mechanisms, participation is limited to one or the other.

obstetric care, including examination of women during the prenatal and postpartum periods, and pediatric care of infants and children. The WIC legislation does not require WIC participants to receive such services, but regulations dictate that local agencies must assure the availability of health services to WIC beneficiaries. Indeed, no agency can be authorized as a WIC sponsor unless it can provide these services either directly or by referral.

WIC is administered federally by the Food and Nutrition Service (FNS) of the Department of Agriculture. Within FNS, the Supplemental Food Programs Division and the regional offices are responsible for program administration. At the State level, WIC is administered by health agencies in the 50 States, the District of Columbia, Puerto Rico, and the Virgin Islands, and by 29 Indian Tribal Councils that function like State agencies.

Federal regulations state that local WIC programs may be administered by any health, welfare, or private nonprofit agency meeting the statutory requirements, but preference must be given to public or private nonprofit health clinics. In practice, the overwhelming majority of authorized agencies—6,585—are health clinics, but 1,280 are welfare programs and community action program (CAP) agencies which subcontract the provision of health services.

FNS allocates funds to State agencies based on formulas developed by the Secretary of Agriculture. The formula for distributing the food grant is designed to reflect a combination of relative infant mortality rates and percentages of infants and children under age 5 who fall at or below 200 percent of the federally defined poverty level. A separate formula for the administrative grant is based on the amount the State is allocated for its food grant, the incidence of rural births in the State, and the salary levels of State and local employees. Receipt of these grants is conditioned upon an approved State plan.

States, in turn, are statutorily required to distribute Federal funds in accordance with an affirmative action plan that places WIC services in areas that have greatest need. In FY 1980, WIC funds apportioned to local agencies served approximately 2.1 million people.

Despite early frustrations caused by the impoundment of funds and a lack of aggressive administration, as well as the necessity for litigation, WIC enjoys the overwhelming support of Congress, health providers, and nutrition advocates. Their enthusiasm is best illustrated by the dramatic rise in funding throughout the program's history. Congress first authorized WIC as a 2-year pilot program with a total appropriation of $40 million for 1973 and 1974. In 1975, when the program had finally gained a foothold and was serving some 500,000 people, Congress reauthorized it for another 3 years, increasing the annual budget ceiling to $250 million. Congress extended the program again in 1978 and provided for annual budget increases. The FY 1980 budget was $758 million; the projected appropriation for FY 1981 is $900 million.

The Panel believes that the WIC program has been successful in providing food and making health services available to those in need. A series of preliminary reports appears to substantiate this view. Despite

some methodological problems, these studies also seem to indicate that WIC is helping to prevent health problems and to improve the health status of its participants.

For example, an initial study sponsored by the University of North Carolina School of Public Health[3] cites evidence of a positive correlation between food and health services made available through WIC, and improvements in nutrition and health status. For infants and children, participation was associated with an acceleration of growth in weight and height, an increase in mean hemoglobin values, and a reduction in the prevalence of anemia. For women, participation was associated with an increased weight gain during pregnancy, an increase in the birth weight of their babies, an increase in mean hemoglobin concentrations, and a decrease in the prevalence of anemia. A major nutrition surveillance study completed by the Center for Disease Control in 1977 relates similar findings.[4]

Recent studies tend to corroborate these positive conclusions. A 1979 study conducted at the Harvard School of Public Health[5] in four Massachusetts WIC clinics, for example, found that the incidence of low birth weight among infants whose mothers participated in the program during the prenatal period was markedly less than among infants whose mothers, although eligible, did not participate. This reduction in the number of low-birth-weight infants produced an additional benefit: a decrease in costs associated with hospitalization. Each dollar spent in the prenatal components of the WIC program resulted in a $3 reduction in hospitalization costs. This was due to the fact that the number of low-birth-weight infants who had required hospitalization was significantly lower for those whose mothers participated in WIC than those whose mothers did not.

Further evidence supports the Panel's belief that WIC acts as an adjunct to good health care during critical stages of growth and development, drawing infants, children, and pregnant women into the health care system and promoting the utilization of essential health services. A study sponsored by USDA and conducted by the Urban Institute in 1976[6] indicates that WIC participation increases the use of health care services. It brings women into health clinics for earlier and more frequent prenatal visits and it increases the number of well-child clinic visits. The Panel is convinced that, by making essential health care services available, WIC is having a beneficial impact upon the health status of the women, infants, and children the program serves.

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[3]Endozien, J. C. *et al. Medical Evaluation of the Supplemental Food Program for Women, Infants, and Children.* Chapel Hill: University of North Carolina, School of Public Health, 1976.

[4]U.S. Department of Agriculture, Food and Nutrition Service. *CDC Analysis of Nutritional Indices for Selected WIC Participants.* Prepared under contract with the U.S. Department of Health, Education, and Welfare, Center for Disease Control, June 1978.

[5]Kennedy, E. T. *et al. Evaluation of the Effects of the WIC Program on Prenatal Patients in Massachusetts.* Cambridge, Mass.: Harvard University, School of Public Health, March 1979.

[6]Bendick, M., Jr. *et al. Toward Efficiency and Effectiveness in the WIC Delivery System.* Washington, D.C.: The Urban Institute, 1976.

BASIS FOR RECOMMENDATIONS

Despite the WIC program's substantial accomplishments in the past several years, the Panel recognizes that it has not yet reached its full potential.

As presently structured, WIC is not available to a significant percentage of those who need it. About 9.1 million women, infants, and children[7] are financially eligible for WIC benefits, but only 2.1 million are now served by the program. While eligibility is also dependent upon nutritional risk, the high correlation between poverty and lowered nutritional status would suggest that many people who qualify by income criteria probably also have nutritional needs for WIC benefits.

Recent USDA figures also indicate the inadequacy of coverage geographically. Currently, 730 of the Nation's 3,042 counties remain without WIC programs. Almost 200 eligible health clinics have petitioned for WIC sponsorship, but potential clients continue to go unserved while these clinics await action on their applications.

The Panel attributes these gaps in coverage to two overriding problems. The first is an absence of health resources needed to fulfill the health services requirement of the WIC legislation. A WIC sponsor must be able to provide health care services to its enrollees either directly or through referral in order to qualify for funds. But many areas without a WIC program probably are classified as "medically underserved" by the Department of Health and Human Services and thus may not be able to comply with the health services standard.

Even where health services are available, potential WIC sponsors may be disregarded. In some areas, State health agencies fund only district or local health departments, ignoring other health or community agencies that could become WIC sponsors. Community Health Centers, for example, are often overlooked by administering health agencies. Current figures indicate that more than 30 percent of the Nation's Community Health Centers do not provide WIC services either directly or by referral.

The second problem is the present level of funding. Many areas have gone without WIC programs—even where health care services are available—because of inadequate funding. In addition, a significant number of WIC sponsors are unable to provide services to all who qualify. Indeed, more than half of all WIC programs have recently requested additional funds to meet the needs of their enrollees. These include 50,000 women, infants, and children whose names will remain on waiting lists, ranked according to medical priority, until supplementary funds become available. The Panel is concerned that the net effect of insufficient funding is to diminish WIC's preventive role and to move toward a restructuring of WIC as a therapeutic program. The Panel believes that this trend should not continue if WIC is to reach its full potential and remain the unique supplementary food program that Congress intended it to be.

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[7]Figure provided by USDA, which bases its estimate on the number of women, infants, and children whose family income is 200 percent below the Federal poverty level.

Even where WIC clinics provide adequate services, not all the infants, children, and pregnant, postpartum, and lactating women who need them take advantage of the programs' benefits. One reason for this is the inability of some WIC sponsors to recruit a significant proportion of potential WIC recipients. Just as important, however, are the problems of client access—particularly lack of transportation, insufficient time or money to travel to the clinic, the absence or the expense of child care, and inconvenient clinic hours. Local programs may aggravate these problems by instituting burdensome administrative procedures. For example, it is not unusual for a WIC clinic to require its participants to visit the clinic once a month. Although necessary in some instances for appropriate followup, this rule frequently results in missed work and school time for some beneficiaries because the vast majority of clinics are open only during weekdays. Moreover, once participants arrive at the agency, they often must wait more than an hour before receiving their food packages or vouchers. While progress has been made in resolving these problems, such difficulties still discourage some potential clients from enrolling in the program and cause others to drop out.

One other issue has a tremendous impact on WIC's accessibility to potential participants. USDA has not yet issued a final regulation to implement the 1978 legislative amendment mandating that WIC income eligibility requirements satisfy the standards for free and reduced-price school meals under the National School Lunch Program. Those standards are set at 125 percent of the poverty level for free meals and at 195 percent of the poverty level for reduced-price meals. Current regulations merely specify that recipients must meet an income standard provided or approved by the State agency. These regulations, which in effect permit WIC sponsors to adopt the same income guidelines used for health clinic services, lead to serious discrepancies in access to WIC benefits. Local sponsors in three States, for example, use income ceilings below 125 percent of the poverty level. At the other extreme, sponsors in 11 States and numerous Indian "State agencies" apply no income standard whatsoever. The Panel is concerned that in many instances these criteria serve to exclude or reduce program participation by low-income women, infants, and children who are nutritionally at risk.

Beyond these fundamental issues of availability and accessibility are problems relating to the program's basic operation. A recent report issued by the General Accounting Office[8] suggests several factors that appear to prevent the food distribution service from working optimally. First, although Federal regulations require that the nutritional risk of each applicant be determined through a medical or nutritional assessment by a competent professional authority, some local clinics are not performing these assessments. Further, the definition of "nutritional risk" varies from State to State, resulting in considerable uncertainty and inconsistency in establishing the nutritional status and eligibility of beneficiaries. Finally,

[8]Comptroller General of the United States. *The Special Supplemental Food Program for Women, Infants, and Children (WIC)—How Can it Work Better?* Washington, D.C.: General Accounting Office, 1979.

some local agencies make only minimal attempts to modify food packages that, based on professional assessments, would supply the kinds and quantities of food needed to satisfy special nutritional requirements. In some cases, appropriate food prescriptions cannot be made because nutritional assessments have not been performed; in others, WIC staff members have not received the professional advice they need to tailor a specific food package to a particular enrollee's condition.

The Panel is particularly concerned about the food prescription policies regarding special formulas for infants and children with medically diagnosed nutritional needs. In many situations, these formulas are incorrectly prescribed. In other cases, special formulas cannot be obtained simply because the regulations make no provision for supplying them. Under current regulations, for example, the WIC program does not offer formulas to children suffering from inborn errors of metabolism unless they are commercially available. While the number of children affected by this policy is relatively small, the consequences to the child and his or her family are enormous. These formulas may be the only way to compensate for this kind of deficiency, yet they remain prohibitively expensive and difficult to obtain for virtually every family whose child qualifies for WIC benefits.

Additional problems impede the provision of health care services. Even when WIC services are sponsored by health departments and clinics, some enrollees do not receive the health services to which they are entitled, often due to the lack of coordination between WIC and other maternal and child health programs. For example, WIC, Title V, and the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program have not established a single comprehensive child health assessment which meets the requirements of each program. As a result, WIC beneficiaries usually must return to their clinics several times in order to receive the WIC nutritional assessment, an EPSDT screening, and routine obstetric or pediatric care. They often must return on other days for treatment services. This process is enormously inconvenient for participants and, additionally, wasteful of scarce resources.

The Panel recognizes that other factors also influence whether WIC participants receive needed health services. A number of local health departments and other WIC sponsors that provide health services simply do not have the capacity to serve all participants. In addition, health services are sometimes offered only at a charge, making cost a barrier to care for many of the poorest WIC beneficiaries. Those States that do not provide Medicaid coverage for women who are pregnant for the first time effectively preclude them from receiving health services they need unless they can pay clinic charges. Moreover, several clinics fail to make referrals or to do followups to assure that appropriate routine and specialized care is furnished.

Also of concern to the Panel is the operation of the nutrition education component of the program. Despite current regulatory requirements, this service has not received the priority it deserves and that Congress intended. To date, FNS has not given the States enough guidance on the purpose and appropriate content of the nutrition education service. The

guidance that States provide to local sponsors differs greatly, and as a result, both the quantity and quality of nutrition education furnished by WIC sponsors vary considerably from program to program.

In addition, two overriding problems affect all components of the WIC program. Both monitoring procedures and technical assistance concerning food distribution, nutrition education, and health care services remain inadequate. With regard to monitoring, for example, State WIC agencies need to make greater efforts to assure that local programs comply with regulatory requirements and provide services that meet minimum quality standards. In particular, State agencies should be monitoring vendors who often allow substitutions for prescribed foods or overcharge for their products. Unless measures are taken to incorporate adequate technical assistance and monitoring procedures into the general program, the Panel questions whether WIC will reach its optimal effectiveness.

PLAN OF ACTION

In making its specific recommendations regarding WIC, the Panel has two major goals: first, to extend the availability of WIC benefits to all those in need; and second, to strengthen the program's ability to improve the health status of its participants. To achieve these goals, the Panel proposes:

- increasing Federal funding for the WIC program
- coordinating WIC program planning and service delivery with the Title V program and other health programs serving infants, children, and pregnant women
- targeting WIC benefits to all infants, children, and pregnant, postpartum, and lactating women in both financial and nutritional need
- expanding Federal and State monitoring and technical assistance efforts

With the exception of the recommendation for increased Federal funding, these recommendations can be carried out through modifications in current regulatory and administrative policies.

Funding for the WIC Program

Changes should start at the Federal level with an increase in congressional appropriations for the WIC program. The Panel recommends that Congress continue its strong financial support of WIC by allocating to the program an additional $150 million per year for the next 2 years. If inflation and food prices remain at their current levels, such an increase would mean that the number of people able to participate in the program during any month in each of the 2 years could be increased by almost 400,000. The Panel also is recommending increases in appropriations for Title V and other health care programs—increases which it believes would expand the availability of health services required under the Federal regulations applicable to WIC. Collectively, these funding

increases would help to bring all WIC benefits to unserved and underserved areas.

Coordination of Services

To improve coordination between WIC and the Federal programs that provide and finance health services, the Panel proposes several remedial measures that touch nearly every administrative aspect of the program. These proposals are intended to strengthen WIC's ability to function as an adjunct to good health care, to simplify and facilitate joint participation in WIC, Title V, Medicaid, and EPSDT, and additionally, to reduce unnecessary duplication of services and administrative costs.

The Panel recommends that USDA, in conjunction with the Federal agencies administering the Title V and Medicaid programs, promulgate regulations creating uniform standards and financing policies for all components of the WIC program intended specifically to affect the health status of its participants. Minimum Federal standards should be established for the nutritional needs assessment, for food package prescriptions—particularly the commercially and noncommercially available infant formulas, and for furnishing or arranging for the provision of health care services. In addition, USDA should enter into financing agreements with the Federal Title V agency and with HCFA establishing that local Title V agencies, and other Medicaid certified health agencies serving as WIC sponsors, will charge the cost of the nutritional needs assessment for Medicaid-eligible infants and children to EPSDT, and similarly, will charge Medicaid or EPSDT for the provision of health services to Medicaid-eligible women, infants, and children. These agreements should become the basis for WIC regulations regarding Federal financing policy.

To ensure effective implementation of these health service and financing policies, USDA regulations must also set out State responsibilities for coordination. State agencies administering WIC should be required, for example, to adopt the State Title V standards and procedures both for nutritional needs assessments and for providing or assuring the availability of obstetric and pediatric services. In addition, WIC agencies should seek the advice and guidance of the Title V staff in setting standards and procedures for tailoring food packages to the general nutritional requirements of the basic categories of WIC clients, and to the individual nutritional requirements of those beneficiaries with special needs. And in at least one area--the provision of health services—the Panel recommends that the separate health department units administering the WIC and Title V programs be directed to develop and sign a memorandum of understanding regarding the availability of health care services for WIC participants.

Regulations also should require State agencies administering WIC to develop an accounting procedure for the nutritional needs assessment that is compatible with those of the State Title V and Medicaid agencies. This accounting mechanism might be based on the staff time apportioned to each program or the ratio of participants eligible for the different programs. Assuming that uniform service standards are in place, it then

would be possible for WIC sponsors to use Medicaid as first-dollar coverage for nutritional risk assessments as well as for health care services.

An additional proposal for improving coordination is to mandate that State agencies establish new WIC programs and enlarge existing ones according to an approved State plan for maternal and child health services, provided that the plan meets WIC's statutory and regulatory affirmative action mandates. The Panel strongly recommends that this plan be developed by the State Title V agency[9] with the approval of the State WIC agency. Integrating the planning processes for health and nutritional services will assure the development of high quality WIC and health care services in areas of greatest need, and will promote regional arrangements in underserved areas.

The Panel also proposes that the WIC State agencies perform two additional, interdependent functions that will further improve the health-related components of the WIC program: First, State agencies should monitor on a quarterly basis all WIC sponsors to determine whether they are in compliance with Federal and State requirements for screening, food package prescriptions and prices, and health services availability; and second, State agencies should provide technical assistance, as necessary, to bring deficient programs in conformity with appropriate standards and policies.

Additional Recommendations

Beyond initiatives aimed at achieving greater coordination and cooperation among the various health-related programs and between the State and local agencies that administer them, USDA must take several other steps in an attempt to expand and strengthen the WIC program. Foremost among these should be regulatory revisions that would target WIC benefits to all people in eligible categories who need WIC's services.

National Income Eligibility Standard

The establishment by regulation of a nationwide income eligibility standard for participation in the WIC program should be a top priority. The Panel recommends that States be required to fix the income standard between 125 percent and 195 percent of the federally defined poverty level.[10] Such a standard will ensure that WIC benefits are targeted at women, infants, and children from low- and moderate-income families. At the same time, it still will permit each State to exercise some flexibility in selecting a specific standard to apply.

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[9]The Panel's recommendations for the broad planning responsibilities of the State Title V agencies are described in detail in chapter 2 of this volume.

[10]This is the same standard the Panel is recommending for States that elect to set income eligibility guidelines for Title V health services. This standard would not apply to preventive and diagnostic services, which the Panel believes should be available at no charge.

Selection of WIC Sponsors

USDA also should promulgate regulations that will help ensure that health care services are available to all WIC participants. Under such regulations, States should be required to obtain from each applicant agency a detailed analysis of its capacity to make health care services available to all WIC beneficiaries, either directly or through contractual agreements. To do this, the agencies may have to seek out services in the private sector, including practicing physicians, health maintenance organizations (HMOs), hospital outpatient departments, and nurse practitioner clinics. This process may also involve the evolution of more creative arrangements, such as the use of a list of private physicians who, on a rotating basis, are willing to provide health care services. State Title V staff members should be required to assist applicant agencies in identifying these resources.

The Panel believes that it is imperative that States give equal and unbiased consideration to all agencies seeking WIC sponsorship—not just health clinics—that are capable of meeting WIC's requirements. Additionally, in some instances, candidates should be considered even if they are unable to comply with all the health service requirements outlined here. For applicants from medically underserved areas, a temporary waiver of the health service requirement should be permitted so that WIC nutritional benefits can be made available. Such a waiver, however, would have to be approved at the State level and explained fully in the State plan. In any event, no applicant should be without a final means for redress; thus, the Panel maintains that all petitioners denied WIC sponsorship should have the right to appeal at the Federal agency level.

Program Monitoring, Enforcement, and Technical Assistance

At the Federal level, greater attention should be given to WIC's monitoring activities in order to achieve the Panel's twin goals of expanding and enhancing the program. FNS should increase its oversight to assure that States award program funds according to an approved affirmative action plan, develop nutrition education programs that can be implemented locally, and ensure that WIC sponsors make health services available and meet all program requirements. In keeping with the Panel's desire to coordinate all health-related services, these efforts should be made in cooperation with other agencies, including the Federal agency administering the Title V program.

FNS also should be more aggressive in using its enforcement powers. Statutorily authorized sanctions should be applied to State WIC agencies that do not comply with all USDA program requirements. Unless such penalties are imposed, the Panel believes that agencies will have little, if any, incentive to meet Federal standards and guidelines.

Finally, the Panel's plan for implementation calls for improvements in FNS technical assistance policies. WIC evaluations, along with other research findings, should be disseminated to State and local program

directors. Private physicians also should be kept informed about the program's activities. On a broader level, FNS should join with the Federal Title V agency in developing nutrition education manuals and additional resource materials as well as conducting WIC personnel training programs.

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CHAPTER 5

P.L. 94–142: THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT

MAJOR RECOMMENDATIONS

- Clarify Federal policy regarding the children covered by the law and the services they are to receive.
- Require that existing health and mental health agencies and professionals, both public and private, be used to the maximum extent possible in implementing the P.L. 94–142 mandates to locate, identify, and evaluate children with handicapping conditions, and to deliver required health and mental health services.
- Assure that in-service training in the special needs of the handicapped is made available to education and health personnel involved in identifying children with handicapping conditions, and in developing and implementing individualized education programs for those children.
- Expand Federal and State monitoring, technical assistance, and enforcement activities to ensure full compliance with the law.
- Assure that individualized education programs are based on appropriate physical and mental health information and expertise and that the confidentiality of health and education records is maintained.
- Bring Federal appropriations for P.L. 94–142 up to the authorized level.

PROGRAM DESCRIPTION AND ACCOMPLISHMENTS

The enactment of Public Law 94–142, the Education for All Handicapped Children Act, in 1975, marked the culmination of a "revolution" in educational opportunities for handicapped children. The Act was

passed in response to a growing recognition by the courts of the rights of handicapped children and the accompanying costs of providing them needed services.

The legislation modified the provision for State grant assistance under Part B of the existing Education of the Handicapped Act[1] to require that "a free appropriate public education" be made available for all handicapped children aged 3–18 by September 1980 and aged 3–21 thereafter.[2] The law applies to all handicapped children regardless of the severity of their disabilities and their families' ability to pay for services.

Covered by the Act are all children who are handicapped and who, because of their impairments, require special education and related services. They include children who are mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired, or multihandicapped, as well as children with specific learning disabilities. For children falling within any of these categories, States must provide both

- individualized instruction designed to meet the child's special needs, and
- related or supportive services necessary for the child to benefit from the individualized instruction program

Related services include school health services, speech therapy, psychological services, physical and occupational therapy, counseling services, medical services for diagnostic or evaluation purposes, and parent counseling and training. The special education and related services are to be furnished in accordance with a written individualized education program (IEP) developed jointly by parents, teachers, and other appropriate individuals.

To receive a Federal grant under the Act, States must comply with the following conditions, even if they must increase State and local funding to do so:[3]

- States must locate, identify, and evaluate every handicapped child within their jurisdictions (the "child find" system) and devise methods for determining which children are not receiving needed services to which they are entitled.
- Evaluations of handicapped children must be conducted in a nondiscriminatory manner.
- Children must be placed in the least restrictive environment consistent with their special needs.

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[1]Title 20 U.S.C. Section 1401 *et seq.* (1976 & Supp. II 1978).

[2]Under limited circumstances, States are not required to make a free appropriate public education available to children aged 3–5 and 18–21. Such is the case if (1) State law expressly prohibits or does not authorize the expenditure of public funds to provide education to nonhandicapped children in any of these age groups, or (2) the requirement is inconsistent with a court order which governs the provision of free public education to handicapped children in that State.

[3]In addition to P.L. 94–142, recipients of Federal financial assistance must comply with Section 504 of the Rehabilitation Act of 1973. This section prohibits those receiving Federal funds from discriminating against persons on the basis of their handicaps. Subpart D of the regulations implementing Section 504 provides that recipients operating public elementary and secondary school programs must ensure that each child receives a free appropriate public education. Many of the specific requirements are similar to those contained in the regulations implementing P.L. 94–142.

- Parents must be given fundamental due process rights, including an impartial hearing on any matter concerning the evaluation, placement, or provision of a free appropriate education for their children.
- States must establish in-service training for general and special educational, instructional, related services, and support personnel.
- States must afford all services and guarantee all rights to children in private schools or facilities as well as to those in public schools.

These requirements make P.L. 94–142 unique among Federal education grant programs: while other programs also have detailed prerequisites on the use of Federal funds, P.L. 94–142 goes one step further by guaranteeing certain rights to handicapped children and their parents without regard to the level of Federal spending.

P.L. 94–142 is administered federally by the Office of Special Education (OSE) within the Office of Special Education and Rehabilitative Services (OSERS)[4] in the Department of Education. OSE is responsible for developing policy for the program, distributing grants to States, and ensuring that States are properly and efficiently administering P.L. 94–142 funds. In addition to P.L. 94–142, OSE administers programs serving handicapped children under P.L. 89–313 (education for disadvantaged handicapped children in institutional settings) and coordinates policy with a number of other Federal programs including several Social Security Act programs: Title V Maternal and Child Health, Title XX Social Services, and Title XIX Medicaid and EPSDT (Early and Periodic Screening, Diagnosis, and Treatment).

At the State level, P.L. 94–142 is administered by a State educational agency (SEA). Although the State is charged with making available a free appropriate public education for every handicapped child, the SEA has overall responsibility for ensuring that P.L. 94–142 is properly implemented and administered. Congress established this line of responsibility "... so that the failure to deliver services or the violation of the rights of handicapped children would be squarely the responsibility of one agency."[5] The SEA is responsible not only for distributing P.L. 94–142 funds to local educational agencies (LEAs), but also for supervising educational programs for handicapped children in the State and ensuring that they are in compliance with SEA education standards.

The LEAs are responsible for designing and providing special education and related services to handicapped children in accordance with the requirements set forth in the Act.

Responsibility for providing funds to satisfy the requirements of P.L. 94–142 is shared among the Federal, State, and local governments. Since 1978, the Federal portion has been determined by a State grant entitlement formula. This formula is based on the number of handicapped children aged 3–21 receiving a free public education in a State multiplied by a percentage of the nationwide average per pupil expenditure. This

[4]Before the establishment of the Department of Education, the Bureau of Education for the Handicapped (BEH) was responsible for administering P.L. 94–142.

[5]U.S. Senate Report No. 168, 94th Congress, 1st Session, *The Education for all Handicapped Children Act*, June 2, 1975.

percentage was 5 percent in FY 1978 and will increase to 40 percent in FY 1982. Although initial appropriations kept pace with this formula, recent appropriations have fallen considerably behind. The advance appropriation for FY 1981 is $874.5 million, or only 40 percent of the total Federal contribution needed to meet the formula.

Some Federal funds are also available in the form of preschool incentive grants, which are generated by double-counting the population of eligible children aged 3–5 years in the State. They differ from the basic grant in that States may retain or distribute incentive grant funds as they desire. States tend to allocate the moneys as (1) State projects, (2) project grants to local educational agencies, or (3) formula grants. In the academic year 1978–79, all States except New Mexico, Arizona, and Wyoming received preschool grants, which totalled $17.5 million nationwide.

In addition to these Federal funds, States may use any other available Federal, State, local, and private sources of support to meet the requirements of P.L. 94–142. Insurers and other third-party payers are not relieved from any otherwise valid obligation to supply or pay for health services provided to a handicapped child.

Early analyses of the program[6] indicate that a strong beginning has been made in meeting the needs of handicapped children. In 1979, 3.9 million children, approximately 75 percent of the Nation's handicapped school-age population, were receiving a free appropriate public education. By comparison, in 1966, before the enactment of any Federal legislation on behalf of handicapped children, only 1.2 to 1.8 million children were being served. In the last 2 years alone, 230,000 children have been identified as needing the services provided through P.L. 94–142. Moreover, there has been a 10 percent increase over the last 3 years in the number of preschool handicapped children aged 3–5 receiving special education.

These studies also show that as a result of P.L. 94–142, physical therapy, occupational therapy, adaptive physical education, and special transportation have become available at no cost to parents of handicapped children. In addition, the Act is credited with increasing by 40 percent the number of previously institutionalized children served by local schools since 1975.

In light of its overall concern with the planning and coordination of programs affecting maternal and child health, the Panel notes that on another front the Act has made progress that merits attention.

The Federal Government supports nearly 130 different programs for handicapped citizens, a number of which are relevant to the operation of P.L. 94–142, including Title V's Maternal and Child Health and Crippled Children's Services (administered under the Bureau of Community Health Services), the Disabled Children's Program (administered under the Bureau of Community Health Services), Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program (administered by the Health Care Financing Administration), Intermediate Care Facilities for

[6]To date, the evaluation of P.L. 94–142 has been extremely limited, in part because the law has been in effect only 3 years. A January 1979 report prepared by the Bureau of Education for the Handicapped, a subsequent update (August 1979), and a 1980 Congressional Research Service report are the major reviews available. Both sources focus on compliance issues—who is being served, at what cost, and with what services. No national evaluation of program outcomes is yet available.

the Mentally Retarded (administered by the Health Care Financing Administration), and Community Mental Health Centers (administered by the National Institute of Mental Health). In the past, the disparate nature and detailed regulations of these programs have forced families of handicapped children to wind their way through a complex maze to obtain needed services.

P.L. 94–142 has provided the impetus for bringing a semblance of order into this system. Since the law's enactment, the Department of Education[7] has undertaken a major effort to promote interagency coordination. At the Federal level, major agencies providing services to handicapped children have agreed to attempt to delineate some specific roles and responsibilities for each agency. For example, written agreements are currently in effect between OSERS and the Bureau of Community Health Services (BCHS), the Health Care Financing Administration (HCFA), the Rehabilitation Services Administration, the Administration for Public Services, the Administration for Children, Youth, and Families, and the Bureau of Occupational and Adult Education.

Especially important to the delivery of health services is the joint policy statement issued by the Bureau of Education for the Handicapped (BEH) and BCHS in 1978, which contains a commitment by both agencies to explore areas of collaboration among the programs they administer. Among other things, BEH and BCHS agreed to provide a forum for reviewing regulations and policies to minimize the duplication of efforts and gaps in services and to respond to problems identified by States.

The joint policy initiatives between the Office of Education and HCFA are also critical to the effective and efficient delivery of health services. In 1978–79, these agencies developed several documents designed to increase coordination between P.L. 94–142 and EPSDT. In a joint policy statement, they acknowledged the desirability of providing access to EPSDT services through schools whenever possible and pledged to take specified actions to accomplish this goal. Moreover, HCFA has issued memoranda encouraging Medicaid agency cooperation with State health and vocational rehabilitation agencies, Title V grantees and other health care providers, as well as SEAs.

Impressive as they are, numbers and interagency agreements do not convey the full import of P.L. 94–142. Available evidence indicates the Act has had a major beneficial impact on the lives of handicapped children and their parents. Witness, for example, the recent testimony of one Minnesota parent before the House Committee on Education and Labor:

> When I look back on my experience before the passage of the law, I have painful memories of the many struggles associated with obtaining appropriate educational programming for my son. It was my perception that I was merely requesting what was his basic right, but I was made to feel that I was asking for too much and my

[7] In April 1980, the Department of Health, Education, and Welfare was divided into two independent departments: the Department of Health and Human Services and the Department of Education. Prior to that date, programs now administered through the Department of Education were administered through the Office of Education (OE) which was one of the operating components of the Department of Health, Education, and Welfare.

requests were not received kindly. For him it was a question of inappropriate services, for others it was often a question of no services at all. ... It was the rare parent who was able to move the system to provide service for his or her handicapped child, for most parents do not know where to go or how to begin.

If it were not for P.L. 94–142, Minnesota would not have the fine special education statute it has today. Today parents have more input. Today schools cannot base their decisions regarding handicapped children solely upon administrative convenience, and although today Public Law 94–142 may not yet be fully implemented, at least we have a good beginning.[8]

The Panel believes that the major accomplishment of P.L. 94–142 has been the revolutionary change in attitude toward handicapped children. Undoubtedly, much work remains to be done before this attitudinal change is transformed into a comprehensive service system to meet all the needs of handicapped children. But at least in terms of educational opportunities, the framework is now in place to ensure that these children receive the individualized instruction and related services they require.

BASIS FOR RECOMMENDATIONS

Although substantial progress has been made in meeting the needs of handicapped children, the P.L. 94–142 program has not yet lived up to its full potential. Several general problems affect the overall performance of the program.

The Panel is troubled, for example, by the wide State-to-State variation in the number of children served in the first full year in which P.L. 94–142 was in operation. Initial estimates were that approximately 10 percent of the children in each State would be identified and served as handicapped. In practice, however, the percentages range from a low of 5.2 percent to a high of 11.5 percent. It is possible, therefore, that States with low percentages may be missing as many as half of all eligible children.

The Panel attributes this uneven level of activity to several factors, two of which are especially significant. First, States were in different stages of preparation when P.L. 94–142 was enacted. Massachusetts, New Jersey, and Michigan, for example, were prepared for P.L. 94–142 because they already had comprehensive education laws of their own in place. At the other extreme, many States without such programs were forced to implement P.L. 94–142 with virtually no previous experience or resources.

Second, the definition and assessment of specific handicaps, especially learning disabilities and emotional disturbances, tend to vary from State to State. As a result, a child may qualify for education and related services in one State but not in another. This situation is caused by a lack of uniform standards and guidelines, which to some extent reflects the

[8]Goldberg, M. Statement before the Subcommittee on Select Education of the House Committee on Education and Labor. *Oversight on Education for All Handicapped Children Act*, Part 1, October 11, 1979, p. 151.

imperfect state of the diagnostic art. A better understanding of such childhood problems as poor selective attention, excessive activity, developmental delay, and behavior dificulties is needed so that professionals can more easily reach consensus on which children need help.

Another problem of concern to the Panel is the inadequacy of early intervention efforts. The goal of providing services to all children with handicaps from birth to age 21 is explicit in the law, although no specific deadlines are set. Nevertheless, P.L. 94–142 includes provisions for developing early identification and early intervention programs in States as a step towards achieving this goal. These provisions stem from the current expert conviction that intervention is more effective than remediation because it relieves suffering sooner and often eliminates or reduces secondary consequences for the child and his family.

While a number of impressive model programs have begun to document substantial positive effects of early intervention, the Panel is concerned that so few programs are available. P.L. 94–142 is, above all else, an entitlement program; thus, the situation in which some young children receive services and others do not is contrary to the intent of the law.

The problem of misclassifying specific individuals or whole groups of children also disturbs the Panel. Current figures indicate, for example, that the diagnosis of mental retardation is made far more frequently in some southeastern States than it is in other parts of the Nation. While the variation may reflect a truly different prevalence of retardation, it also may occur because of the use of culturally biased tests, overreliance on one measure of function—for example, intelligence quotient (IQ)—or racial discrimination.

Several additional problems hamper P.L. 94–142's effectiveness even for those handicapped children participating in the program. Too many handicapped children do not have an IEP or do not have one that is truly individualized. Some IEPs are simply prepackaged assessments with identical service recommendations for each child with a certain handicap; other plans may consist of different services, but the schools have placed a ceiling on the total dollar amount that can be spent on each student. Furthermore, IEPs often call only for services that are already available in a school system rather than for services the child actually needs.

Services agreed upon and prescribed for children are not always readily available, however. This is particularly true for physically handicapped children whose needs are often ignored as schools struggle to address the problems of learning disabled and mentally retarded children. It is not unusual, therefore, for children whose needs have been identified and for whom service plans have been written to be placed on waiting lists for months, depriving them of equal educational opportunities. Children also are often switched back and forth between schools because of changes in their service needs and the ability of schools to meet them.

Schools have difficulty in accommodating handicapped children in other ways as well. For example, schools traditionally provide services only 9 months a year, 5 days a week. The educational needs of many seriously handicapped children are continuous, however, and they may require services during summers, vacations, or on weekends. School

systems are often ill-equipped to provide services during these periods, yet a recent judicial interpretation of P.L. 94–142 appears to indicate that they must do so.[9]

The Panel believes that the failure to make services mandated by P.L. 94–142 fully accessible and available is largely due to the excessive financial burden that has been placed on State and local educational agencies in providing a free appropriate public education to handicapped children. Indeed, because congressional appropriations for P.L. 94–142 have fallen significantly below the expected level, these agencies now bear the major burden for funding P.L. 94–142 programs. Unless Congress increases funding in the very near future, many of the problems outlined above will remain unresolved.

Additional funds to implement the mandates of P.L. 94–142 could possibly come from Medicaid and other health insurance programs through reimbursement for the health and mental health services provided under the Act. However, restrictions on Medicaid eligibility and limitations on service coverage preclude many handicapped children from receiving the services they require. Moreover, reimbursement from private insurers is often denied because services are deemed to be education-related rather than health-related.

The Panel believes, however, that shortfalls in funding do not fully account for current deficiencies in the operation of the P.L. 94–142 program. Because of their lack of clarity and precision, the Act itself and its accompanying regulations also must shoulder some of the blame. For example, terms such as "identification," "education," and "related services" are defined and described somewhat ambiguously. There are often questions, therefore, as to how children in need of special education and related services are to be identified, when their education should include services that are sometimes viewed as care and treatment by health and social welfare providers, what constitutes a related service, and who is to provide and pay for it.

The legislation and regulations are also vague in their delineation of specific roles and responsibilities for carrying out the mandates of P.L. 94–142. There is a general lack of understanding, for example, that the State, and not the SEA, is responsible for ensuring that every child in the State receives a free appropriate public education, and that the SEA has been delegated the sole responsibility for ensuring compliance with the requirements set out in P.L. 94–142.

Furthermore, P.L. 94–142 leaves unresolved many issues that touch upon the relationship between health and education and the responsibilities each sector should bear in providing special education and related services to handicapped children. The Act and its regulations do not answer such questions as:

- What is the responsibility of educational agencies in ensuring the quality of required health and mental health services?
- What responsibility do they have regarding the availability and appropriate but confidential use of a child's health and mental health history in developing the IEP?

[9] *Armstrong v. Kline*, 476 F. Supp. 583 (E.D. Pa. 1979), *aff'd* 485 F.2d 1298 (3d Cir. 1980).

- What authority do occupational and physical therapists, nurses and education personnel have in making recommendations for health service needs?

The Panel is concerned that such unsettled issues have affected the overall performance of the P.L. 94–142 program.

Another problem inhibiting the effectiveness of P.L. 94–142 is the lack of a coordinated network of services for handicapped children. When Congress enacted P.L. 94–142, it expected that education and health agencies would coordinate the delivery of services. This has not always been the case.

Schools are increasingly recognizing the health needs of their handicapped students, and health professionals are becoming increasingly aware of the functional and educational aspects of their patients' lives. However, there still remains a significant duplication of services (particularly evaluative services), a lack of mutually comprehensible terminology by health, mental health, and education professionals, and inadequate cooperation among agencies to meet the needs of handicapped children. All too often families must seek out health services from a variety of providers, go from agency to agency to obtain funds for supplies and medicines, and painstakingly piece together a program for themselves and their children. It is not unusual for the mother of a handicapped child to consider advocacy with agencies and schools her full-time job. Services may be available, but they are often provided in far-flung locations and by a variety of professionals—many of whom require extensive and exhaustive probes into the families' social and financial status. Agencies may all show concern, but few can provide a coordinated package of needed services. P.L. 94–142 was responding to this problem when it placed the responsibility of coordinating services with the SEAs. In practice, however, these agencies have been unable to live up to this responsibility.

The Panel believes that three key factors inhibit effective and efficient coordination. First, while there is a definite education sector—the public school system—which has a relatively stable and replicable structure from town to town and State to State, there is no parallel health system. Most children receive their health care in the private sector from individual practitioners, hospitals, and clinics providing various services and using several payment mechanisms. It can become quite difficult, therefore, for the education sector to determine with whom it is supposed to coordinate.

Second, notwithstanding the fact that each piece of legislation pertaining to services for the handicapped generally provides for coordination with other programs, definitions and mandates among programs are not always consistent in their approaches to handicapped children.

Third, although the Federal Government has initiated a major effort to improve interagency cooperation by focusing primarily on the negotiation of Federal, State and local agreements, many of these agreements are merely promises to cooperate. They do not include comprehensive procedures that address the major areas of overlap, the determination of which services are appropriate, the qualifications of the persons providing the services, or the mechanism for paying for them.

Other problems also bear upon the ability of P.L. 94–142 to accomplish its goals. One, which is a major deficiency in the program, is the lack of

technical assistance to help States overcome their difficulties in providing adequate special education and related services.

The Panel contends that many school systems are falling short of meeting the requirements of P.L. 94–142 because the skills required to do so are not sufficiently developed in the educational system. Teachers and educators are not always knowledgeable about community agencies. Also, they are not trained in the integration of health, social, and psychological data and consequently are not necessarily equipped to manage health problems in the classroom. Traditional training of public school teachers does not, for example, extend to techniques such as signing or handling gross motor seizure in the classroom, yet such knowledge may be needed to work with handicapped children in the least restrictive environment.

Health and mental health professionals working in schools also may not be prepared to deal with the special needs of handicapped children. The Panel is particularly concerned about the ability of school nurses to play a leading role in the implementation of P.L. 94–142. Many schools have no school nurses at all; others are served by health department nurses who can spend only a few hours a week in the school because of other commitments and responsibilities. School nurses, like most educators, often have insufficient information about community-based agencies that provide required services. In addition, many are ill-prepared to meet the needs of handicapped children, or else have not kept abreast of current developments related to the diagnosis and treatment of handicapping conditions.

Another limitation of the program is the insufficiency of monitoring procedures to identify noncomplying P.L. 94–142 programs and the lack of enforcement efforts by the Federal Government to bring such programs into conformity with the Act. Until improvements are made in these areas, P.L. 94–142 will not realize its full potential.

PLAN OF ACTION

The primary purpose of the Panel's proposed plan is to maximize the likelihood that medical, health, and mental health services required by P.L. 94–142 will be delivered to handicapped school-aged children in the most appropriate and effective manner. The Act and its accompanying regulations offer little guidance as to how this goal can be accomplished.

It is the Panel's considered opinion that health and mental health services can best be provided by, or under the direct supervision of, appropriate community agencies. When such services could be furnished more effectively and efficiently in the school setting, these agencies should assign staffs to the schools. There basically are only two circumstances under which the Panel believes schools should hire or contract with health and mental health professionals. One is when the required diagnostic, health, and counseling services are not available through community agencies. The other is when the school can ensure a formal involvement with health and mental health agenices and can assure that its staff will be

included in training, supervision, and other staff development activities of these agencies.

To bring about this community-based system, the Panel proposes:

- clarifying Federal policy with regard to the children covered by P.L. 94–142 and the services they are to receive
- requiring that health and mental health resources be used to the fullest extent possible in implementing P.L. 94–142, and in delivering and financing required health and mental health services
- assuring that appropriate in-service training is made available to education and health personnel
- expanding Federal and State monitoring, technical, and enforcement activities
- ensuring that IEPs are based upon appropriate physical and mental health information and expertise
- increasing Federal funding for P.L. 94–142 to the authorized level

The Panel supports the basic precepts of P.L. 94–142. Therefore, the Panel's strategy for implementing its recommendations generally relies on regulatory and administrative actions.

Coordination of Federal Activities

Changes should emanate from the Federal level, beginning with the development of a strong, coordinated network of services for handicapped children. The Panel urges that all Federal agencies involved in the financing and delivery of education, health, and mental health services take whatever steps are necessary to coordinate their efforts in implementing P.L. 94–142. Specifically, the Panel recommends that the BEH/BCHS joint policy statement be carried out to the fullest extent possible so that the responsibilities of health and educational agencies are clearly delineated. Action on the OE/HCFA joint policy statement also should be taken to ensure that Medicaid reimbursement for health and mental health services required under P.L. 94–142 is provided for Medicaid-eligible children. New interagency agreements must be developed as well. The Panel recommends in particular that agreements be reached between the National Institute of Mental Health (NIMH) and OSERS specifying how mental health services will be made available.

In addition, the Panel recommends that appropriate Federal agencies issue joint guidelines, informing State and local educational, health, and mental health agencies of the purpose and result of Federal coordination efforts. These State and local agencies should be provided with the technical assistance they need to understand and better implement P.L. 94–142. Additionally, the Panel proposes that appropriate Federal agencies undertake joint research efforts to develop definitions of handicapping conditions and standards for services.

To promote the development of a coordinated network of required services, the Panel also recommends that Federal regulations and

supporting guidelines be amended to clarify the role of health and mental health agencies and professionals in providing special education and related services to handicapped children. More specifically, the Panel proposes that regulations implementing the "child find" requirements of P.L. 94–142 be amended to provide that health and educational agencies must work cooperatively to evolve a plan for locating and identifying all handicapped children, and to define "child find" responsibilities according to primary contacts with the child. Such measures are essential to the development of effective early identification and early intervention programs.

Enlisting Appropriate Service Providers

The Panel proposes that regulations pertaining to the related services component of the Act be revised to require that educational agencies identify appropriate health and mental health agencies to serve as expert consultants in implementing this facet of the P.L. 94–142 program. Such modifications should require educational agencies to establish cooperative arrangements with health and mental health agencies so that referrals can be readily made for the diagnosis or evaluation of a handicapping condition.

Educational agencies also should be required to make every effort to utilize all existing health and mental health resources to deliver and finance health and mental health services before they can expend funds allocated under the Act. The Panel suggests that specific use be made of the services provided by Title V's Crippled Children's (CC) Services and Community Mental Health Centers (CMHCs). But other health and mental health resources should be employed as well. Among public agencies, educational agencies should look to maternal and child health projects, comprehensive health centers, Title XX supported services, local health departments, and nursing agencies to provide needed services. In the private sector, educational agencies should turn to hospitals, health maintenance organizations (HMOs), private physicians, therapists, and other health and mental health providers for assistance.

Public and private insurance mechanisms, such as Medicaid or Blue Cross/Blue Shield, should be used to pay for required services. Medicaid already requires first-dollar coverage for needed health-related services, but States must be better informed about this policy. On the other hand, the policy of many private insurance companies is not to reimburse for related services mandated by P.L. 94–142. The Department of Education, therefore, should develop incentives through which States would be encouraged to require payment by private insurers for services that would be covered if they were not recommended or provided by an educational agency. Consideration should also be given to withholding Federal contracts from companies that engage in this practice.

Finally, the Panel recommends that guidelines be issued encouraging LEAs to hire or contract with an individual health or mental health professional only when services are unavailable through community

agencies or when the school can ensure a formal relationship with community-based agencies through which health and mental health resources will be coordinated. In such instances, the agencies should make every effort to secure financial support for the child from appropriate health or mental health resources.

Additional Recommendations

Beyond these more general proposals, the Panel recommends some refinements of the regulatory framework specifically directed at certain terms and activities described in P.L. 94–142.

Clarification of Terms and Responsibilities

The first such proposal concerns the terms "identification," "education," and "related services." Utilizing the expertise of NIMH and the Federal agency administering the Title V program, the Department of Education should clarify by regulation and in some instances, policy memoranda, the meaning of these concepts. This is particularly important for the term "related services," which has been a source of misunderstanding from the beginning of P.L. 94–142. For example, under current regulations concerning "related services" it is not clear whether "counseling services" include psychotherapy and family therapy. The regulations should be amended to include these services among the list of related services the Act provides for and to specify that they be furnished by qualified professionals such as social workers and psychologists. Furthermore, since a medical diagnosis may be necessary to ensure private and public reimbursement for these services, the Panel recommends that the Department issue a policy memorandum to explain that the Act covers medical services provided for this purpose.

A second recommendation is for an explanation of the specific role of the SEA in providing education and related services. The Panel proposes that the Department of Education release a policy memorandum clarifying that the State, and not the SEA, must ensure that a free appropriate public education, including related services, is furnished to each handicapped child in the State. The memorandum should explain that the SEA may redelegate its supervising, standard-setting, and monitoring responsibilities to health and mental health agencies so long as the SEA retains ultimate responsibility and the policies promoted by other State agencies are consistent with the minimum standards set out in P.L. 94–142.

Development of the IEP and Coordination of Services

The Panel believes that the process for developing the IEP needs clarification as well. Regulations should be adopted that specify the requirements for the provision of health and mental health information and the role of health and mental health professionals in the evolution of

the IEP. Such regulations should encompass a number of ideas that the Panel maintains are important in ensuring that the IEP is based on appropriate physical and mental health expertise.

First and foremost, these regulations should require that the LEA designate or employ an appropriately qualified health professional to manage the related services component of the IEP.[10] Under the regulations, this "health care coordinator" would be responsible for obtaining—with the parent's consent—all pertinent needed data from the child's primary physician and from any consultants or special medical programs in which the child has participated. The health care coordinator also would be responsible for arranging any additional medical evaluations the child might need through appropriate community resources, including CC services, CMHCs, local and regional hospitals, and other public and private facilities.

If a child exhibits a health or mental health problem, regulations should mandate that the formal meeting to discuss the IEP with parents include someone skilled in understanding medical information and, where appropriate, a mental health professional from a local agency. When the child's primary care physician cannot or will not perform this role, the designated health care coordinator should substitute. The health care coordinator, however, should be in contact with the child's primary physician before the IEP meeting; after the meeting, the coordinator should make the proposed IEP available to the child's doctor for review to ensure consistency between medical and educational treatments. Regulations should also encourage the participation of such health personnel as nurses and physical or occupational therapists, where appropriate, and permit them to make recommendations on the nature, frequency, and amount of service required. Nevertheless, such recommendations—as well as all other medical and health components of an IEP—should be approved by the child's primary care physician before being formally incorporated into a specific plan.

Confidentiality of Records

The Panel recognizes that Federal statutes and regulations to protect education and medical records of handicapped children are somewhat limited. The Family Educational Rights and Privacy Act requires that an educational agency have a written release from the child's parent before disclosing personally identifiable information from a student's education record. Parental consent is not required if the disclosure is made in the child's school to other school officials who have legitimate education interests. Protective measures that are more directly related to handicapped children and their parents are specifically mandated by P.L. 94–142 and its implementing regulations.

The Panel believes, however, that further safeguards are needed. It recommends that the Department of Education develop additional regulatory protection for the educational and medical records of handi-

[10]The Panel urges that, in the future, community case management units be developed to coordinate and monitor all children's services, including those required as related services for handicapped children under P.L. 94–142.

capped children. Current regulations should be amended to require that the contents of an IEP, any notes from an IEP meeting, and all supplemental information—home visit reports, for example—be considered confidential and that the educational agency not disclose any part of that information without informed written consent from the child's parent. Under these regulations, parents should be given the right to determine who may be a party to any part of an IEP meeting in which confidential information is discussed. Finally, the Panel recommends that the regulations specify that parents be informed in writing of all their rights relating to issues of privacy and confidentiality.

In-Service Training

In-service training for personnel who deliver services required by P.L. 94–142 is another mandated activity that needs improvement. Current regulations do not include a role for existing health and mental health resources. The Panel recommends, therefore, that these regulations be revised to require that health and mental health professionals—particularly those associated with maternal and child health, crippled children's, and community mental health programs—participate in developing and delivering in-service training to general and special education personnel, including members of the school's instructional, related services, and support staff. Similarly, special education personnel should be required to work with health and mental health professionals in evolving health-related in-service and preservice training programs.

Such programs should include familiarization with various handicapping conditions and related support care needs, and should be aimed at changing attitudes among education and health personnel. In addition, in-depth training on specific handicaps, such as hemophilia, should be provided on a consultation basis to individual education and health personnel in the schools.

Technical Assistance, Program Monitoring, and Enforcement

Increased and improved technical assistance also is needed to promote and expand P.L. 94–142 services. This assistance should include information about public and private funding resources for health and mental health services, along with personnel training materials developed with the assistance of the Federal Title V agency.

P.L. 94–142 will never reach its full potential, however, until the Department of Education enforces full compliance with the mandates of P.L. 94–142 and its accompanying regulations. A strong enforcement posture will be particularly critical if fiscal pressures result in reduced services for handicapped children in direct violation of the specific mandates of P.L. 94–142. The Panel suggests that OSE and the SEAs monitor the implementation of P.L. 94–142 through statistical reports, complaint investigations, and periodic onsite reviews, especially with regard to the development of the IEP and the provision of related services. The Panel recommends further that OSE pursue the enforcement of full compliance with P.L. 94–142 and with other civil rights statutes, both

through its own efforts and in cooperation with other Federal enforcement agencies.[11]

Program Funding

The Panel's final recommendation relates to funding. The Panel urges that Congress appropriate funding for P.L. 94–142 at the authorized level. Although the Panel recognizes that the mandates of P.L. 94–142 apply irrespective of the level of Federal funding, it believes that increased Federal support is necessary to increase the likelihood that the congressional promise of appropriate educational opportunities for all handicapped children will, in fact, become a reality.

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[11]The Panel commends the Department of Education for its recent report describing the Department's efforts to improve its performance in ensuring equal opportunity for handicapped children. The report, issued on October 15, 1980, is entitled, "The Final Report to the Secretary of the Task Force on Equal Educational Opportunity." Among the most important steps discussed in the report is the signing of a comprehensive memorandum of understanding between the Office of Civil Rights and OSE. This memorandum will help ensure increased coordination between these offices in the Department of Education's efforts to enforce both P.L. 94–142 and Section 504 of the 1973 Rehabilitation Act.

CHAPTER 6

COMMUNITY MENTAL HEALTH CENTERS AND SERVICE SYSTEMS

MAJOR RECOMMENDATIONS

In response to the Nation's need for comprehensive mental health services for children and other unserved or underserved populations, Congress enacted the Mental Health Systems Act on September 30, 1980. President Carter signed the legislation into law just 1 week later. The new Act will replace the Mental Retardation and Community Mental Health Centers Construction Act which was responsible for creating the current network of Community Mental Health Centers. It will not become effective, however, until FY 1982.

In light of this recent development, the Panel's recommendations basically are directed at the mechanisms through which the Mental Health Systems Act will be implemented. Other proposals involve revisions in the substance of the Act itself. All proposals are offered, however, against a background of the failure of Community Mental Health Centers and their enabling legislation to address adequately the special mental health needs of children and youth. More specifically, the Panel makes the following recommendations:

- Develop and expand the availability of mental health services for children, including early detection and treatment of developmental problems and preventive services for children and their families.
- Increase the availability of high quality treatment services for children and adolescents, including hospital and residential care, as well as appropriate community support mechanisms.
- Establish Federal policies to foster the development of mental health services in rural and other underserved areas, and to assure the continuation of existing services—especially those serving minority and low-income families—that deliver needed consultative, preventive, and therapeutic services to children.
- Require Community Mental Health Centers and other federally supported mental health service programs to coordinate their

services with general health care programs, and with education and social service agencies serving children.

- Require Community Mental Health Centers and other federally supported mental health service programs to extend their services into schools, Head Start programs, and juvenile institutions, and to involve families in the delivery of mental health services for children.
- Require State mental health service plans to recognize the developmental needs of infants, children, and adolescents.
- Provide Federal support for research and training activities designed to develop a base of knowledge and expertise for the effective delivery of mental health services to children.
- Increase Federal funding for all mental health services, but especially those for children.

PROGRAM DESCRIPTION AND ACCOMPLISHMENTS

As originally enacted in 1963, the Mental Retardation and Community Mental Health Centers Construction Act[1] (known generally as the "Community Mental Health Centers or CMHC Act") authorized limited Federal financial assistance to States to aid them in the construction of Community Mental Health Centers (CMHCs). Congress believed that such centers could be more effective in treating the mentally ill than the institutional programs of State and county mental hospitals that had been the dominant mode of treatment. The hope was that, ultimately, community-based treatment programs would supplant large institutions in dealing with the Nation's mentally ill.

The 1963 Act gave priority to general hospitals that wished to develop CMHCs as part of their services. To qualify for assistance, each CMHC was required to provide a minimum of five services that included inpatient, outpatient, partial hospitalization, emergency, and consultation and education. Facilities were to be individually designed so as to meet the needs of a CMHC's service or "catchment area."

Initial CMHC funds basically were to be used to build new, and expand existing, facilities. However, through a series of amendments adopted over a 15-year period, Congress broadened the original CMHC program to provide Federal assistance for a number of supportive and administrative activities in addition to appropriations for new services, including those for children.[2] Part F of the 1970 amendments to the CMHC Act created a new program for children's mental health services under which funds were made available for construction and staffing assistance, and for training and evaluation. These funds were authorized for consultation services in both community health centers and specialized treatment facilities. The

[1]Title 42 U.S.C. Section 2689 *et seq.* (1976 & Supp. II 1978).

[2]Throughout this chapter, the term "children" is used to refer to all individuals up to and including age 17. The term "infant" refers to children in their first year of life; the terms "adolescent" and "youth" refer to children ages 12–17. Unless these terms are mentioned specifically, the reader should assume that reference is being made to "children" in its broadest sense.

1975 amendments, however, specifically revoked authorization for the Part F program. At the same time, these amendments expanded the number of services required to be made available by or through CMHCs to include mental health services for children, although no special grant program was established for this purpose.

As presently structured, the CMHC Act bears little resemblance to the original enabling legislation. Indeed, under the current law and its regulations, Community Mental Health Centers must now provide 12 instead of 5 basic mental health services to qualify for Federal financial assistance. These are:

- inpatient services
- emergency services
- outpatient services
- court screening and referral
- followup
- consultation and education
- day care and partial hospitalization
- transitional services
- services for children
- services for the elderly
- alcohol treatment and rehabilitation
- drug treatment and rehabilitation[3]

In most cases, the first six of these service categories must be made available when a Community Mental Health Center is established. CMHCs must phase in the remaining mandated services—including those for children—based on local needs and resources over a 3-year period. Services may be provided at the CMHC itself, at satellite centers through the CMHC staff, or through arrangements with health professionals and others in the CMHC catchment area. When medically necessary, services must be made available and accessible 24 hours a day, 7 days a week.

In addition to these requirements, CMHCs are required to coordinate their mental health services with the services of other health and social service agencies and establish ongoing quality assurance programs. Each center also must have representatives of its catchment areas on its governing board.

The Community Mental Health Centers Act offers six basic grants of limited number and duration. Funds are available (1) to plan Community Mental Health Center programs; (2) for the initial operation or staffing of CMHCs; (3) for CMHC consultation and education services; (4) to convert all CMHCs to full service centers; (5) to alleviate CMHCs' financial distress as needed; and (6) to acquire, remodel, lease, construct, or expand CMHC facilities. Both public and nonprofit private entities may apply for grant funds. No grant will be made, however, unless a State plan for the statewide provision of comprehensive mental health services has been approved by the Secretary of the Department of Health and Human Services (DHHS).

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[3]Rape prevention and control services also may be provided by CMHCs through the National Center for the Prevention and Control of Rape. The Center, which is administered within the National Institute of Mental Health, was established under the 1978 amendments to the CMHC Act.

The CMHC program is administered regionally under regulations and guidelines developed by the National Institute of Mental Health (NIMH) within DHHS. Each of the 10 DHHS regional offices reviews grant applications, provides technical assistance to applicants, and monitors funded programs. The authority for final approval of program grants rests with the National Advisory Mental Health Council, whose members are selected by the Secretary of DHHS with the concurrence of the President.

Currently, 752 Community Mental Health Centers provide services throughout the 50 States, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. In 1977, centers served an estimated 1.8 million people including 396,000 children, or 22 percent of the total.[4] Originally, CMHCs were hospital-based, but over time organizations such as nonprofit groups and special clinics have also been involved in providing services. Total expenditures for the CMHC program over the past 14 years have been approximately $2.2 billion; 7.3 percent of this amount has been spent on services for children through the Part F program.[5]

Although the CMHC Act has undergone substantial revisions over the years, its purpose has always remained the same: the establishment of a nationwide, community-based mental health system. The Panel believes that considerable progress has indeed been made in achieving this goal and is encouraged by a number of signs supporting this view.

Perhaps the most important achievement is that CMHCs are providing mental health services to persons who have traditionally gone without them. There has been a substantial increase in the availability of mental health services to the indigent and to persons living in low-income rural and urban areas. In fact, 54 percent of all patients seen in Community Mental Health Centers have annual family incomes of less than $5,000, and 37 percent of funded CMHCs are in rural settings.[6]

Community Mental Health Centers can also be credited with developing effective public information and education programs about mental health, mental illness and prevention, and available community resources. These programs have resulted in an increase of referrals to CMHCs not only from traditional referral sources such as families and schools, but also from social services, law enforcement agencies, and other community-based organizations.

In addition, Community Mental Health Centers have made significant financial progress: in keeping with Congress' original intention of providing only limited Federal financial assistance for CMHC operation, centers have increased their ability to generate third-party reimbursements for direct patient care services. Receipts from services have more than doubled, from 16 percent of total receipts in 1969 to 36 percent in 1977.

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[4]U.S. Department of Health and Human Services, National Institute of Mental Health, Division of Biometry and Epidemiology. *Provisional Data on Federally Funded Community Mental Health Centers, 1977–1978.* Bethesda, Md.: NIMH Survey and Reports Branch, May 1980.

[5]U.S. Senate, Committee on Labor and Human Resources, 96th Congress, 2nd Session. *The Mental Health Systems Act Report No. 712 to Accompany S 1177.* Washington, D.C.: U.S. Government Printing Office, 1980, pp. 22–23.

[6]U.S. Senate, Committee on Labor and Human Resources, 96th Congress, 2nd Session. *The Mental Health Systems Act Report No. 712 to Accompany S 1177.* Washington, D.C.: U.S. Government Printing Office, 1980, p. 32.

Program accomplishments for children, however, are difficult to assess. Current data are unavailable because existing reporting systems do not identify the number of children served and the services they receive. The few evaluations that are available tend to focus on the administration and operation of the Part F program that was enacted in 1970 and that provided grants to CMHCs and free-standing children's mental health clinics. Although the program was carried out on a relatively limited scale,[7] studies show that the part F program played a critical role in helping to meet the mental health needs of the children and youth who were served under it. Part F programs have been credited with

- increasing the rates of child and adolescent referrals from community caregivers
- increasing direct services to children
- increasing the average number of CMHC full-time equivalent staff members serving children
- increasing the average number of children's indirect services per center[8]

Part F programs produced other significant results in their catchment areas as well. Outreach activities were expanded to include services in the school setting. Contacts with children of indigent families increased; more than 50 percent of the clients who received services through the Part F program lived in poverty areas.[9] Community training activities and consultation services in the community increased also. As a consequence of these and other factors, CMHCs with Part F grants experienced a 49-percent average increase in their caseloads.[10] And by participating in the sharing of staff and resources with other service systems, Part F programs contributed to the development of a better coordinated mental health system.

BASIS FOR RECOMMENDATIONS

Since its inception in 1963, the CMHC Act has accomplished a great deal. But it has also suffered from a number of shortcomings that have impeded efforts to establish an integrated local-State-Federal mental health system and to meet the special mental health needs of the Nation's children and youth.

A basic problem is the insufficiency of CMHC coverage and capacity. The Panel is disturbed that, although the CMHC Act has been in operation for 17 years, more than one-half of the country's population still lives outside the CMHC catchment areas. In many rural areas, resources

[7]One hundred and sixty-one projects were funded through the Part F program. Of this number, only 19 projects were located in CMHCs. The remaining projects were administered by free-standing children's clinics.

[8]Sowder, B. J. *Assessment of Child Mental Health Needs and Programs.* American Technical Assistance Corp./General Research Corp. Contract Report OAD-A-CR-78, March 1975.

[9]Sowder, B. J. *Assessment of Child Mental Health Needs and Programs.* American Technical Assistance Corp./General Research Corp. Contract Report OAD-A-CR-78, March 1975.

[10]Sowder, B. J. *Assessment of Child Mental Health Needs and Programs.* American Technical Assistance Corp./General Research Corp. Contract Report OAD-A-CR-78, March 1975.

are insufficient to meet the Act's basic service requirements. The Panel also is troubled by the inability of some CMHCs to meet the mental health needs of the people living within their catchment areas. Racial and ethnic minorities especially have not been fully served by the CMHC program. In addition to a lack of funding, these problems of service availability and adequacy undoubtedly are caused by insufficient planning, poor management, and deficient monitoring and quality assurance procedures.[11]

More importantly, the Panel believes that the CMHC program has been grossly deficient in meeting the mental health needs of children and youth. Current estimates indicate that at most, only 20 percent of the children who need mental health services are, in fact, receiving them.[12] This low proportion is even more disturbing in light of the fact that there are approximately 70,000 chronically mentally ill children under the age of 18 in the United States today, and 50 to 80 percent of them will retain their disabilities into adulthood.[13]

Even where mental health services are available, they do not sufficiently meet the special needs of children. Although services to children have been among the 12 statutorily mandated CMHC services for the past 4 years, several studies and reports indicate children remain a major underserved population.[14]

While CMHCs provide some traditional outpatient services to children, very few are designed to meet the special requirements of infants and young children with cognitive, emotional, and psychoneurological development problems. The centers also give little attention to children at risk or to disturbed adolescents. These are infants, children, and adolescents who generally require more than the usual mental health services. For example, multidisciplinary evaluations, consisting of such services as nutritional assessments; visual, hearing, and speech tests; psychoneurological testing; and small- and gross-motor skill evaluations often are needed for appropriate treatment.

Also of concern to the Panel is the acute lack of appropriate mental health services for severely or chronically disturbed children and youth. While there has been some improvement in recent years, most of the estimated 2 million children and adolescents with severe mental distur-

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[11]For a more in-depth analysis of the general problems relating to the delivery of mental health services under the CMHC Act, see, for example, Comptroller General of the United States. *Legislative and Administrative Changes Needed in Community Mental Health Centers Programs.* Washington, D.C.: U.S. Government Printing Office, 1979. Naierman, N., B. Haskins, and G. Robinson. *Community Mental Health Centers—A Decade Later.* Cambridge, Mass: Abt Associates, Inc., 1978. Comptroller General of the United States. *The Community Mental Health Centers Program—Improvements Needed in Management.* Washington, D.C.: U.S. Government Printing Office, 1971.

[12]Hersh, S. P. "A Review and Commentary on the Carter Mental Health Systems Act," *The Clinical Psychologist* 32, Summer 1979.

[13]Lourie, I. *Chronically Mentally Ill Children and Adolescents, a Special Report for the National Plan for the Chronically Mentally Ill,* August 5, 1979.

[14]See, for example, U.S. Commission on Civil Rights. *Report: The Age Discrimination Study,* Part 1, December 1977; and Part II, January 1979, Washington, D.C.: U.S. Government Printing Office; The President's Commission on Mental Health. *Report to the President,* Volume I. Washington, D.C.: U.S. Government Printing Office, 1978.

bances[15] are not receiving the services they need. Few CMHCs, for instance, have addressed the reality that a significant number of children need inpatient or residental care. Moreover, because many severely disturbed children and adolescents are covered by P.L. 94–142 (the Education for All Handicapped Children Act) they frequently are placed in special schools or special education classrooms. Educators, however, make little effort to furnish these students with clinical mental health services.

The Panel contends that several factors account for the inadequacy of mental health services for children. First is the environment in which most Community Mental Health Centers operate. CMHCs usually function in relative isolation from other systems designed to serve children, and their linkages with these systems are weak. Consequently, early identification and early mental health treatment interventions do not occur as frequently as they should. Because mental health services are not well coordinated with the health care system, for example, cognitive and affective developmental disorders frequently are not diagnosed or treated in early infancy and childhood. Insufficient outreach and coordination with the local education system often results in the absence of essential mental health services to seriously disturbed children covered under P.L. 94–142, to violent and antisocial children and adolescents, and to other children who are at risk. Poor coordination with the social service system has similar effects upon abused children and children in foster families.

Furthermore, this lack of coordination among service systems undermines efforts to serve the many children who have mental health problems and are also multihandicapped. These children suffer from physical (including nutritional), social, and learning problems in addition to some type of mental disorder. Appropriate treatment for them requires that mental health services be combined with various forms of health care, special education, and family assistance. As currently structured, however, CMHCs do not participate in this kind of comprehensive care.

A second factor contributing to the inadequacy of mental health services for children is the lack of statewide planning. State health and mental health plans generally give minimal attention to children's mental health needs. Consequently, the mental health requirements of some children and adolescents, particularly those who are severely disturbed, are often ignored. The revised National Health Planning and Resources Development Act does call for the integration of mental health planning into the State health planning process, but it makes no specific provision for addressing children's mental health problems, or their relationship to other health service needs, particularly the need to provide some children and adolescents with more than the traditional mental health services. Under current law, therefore, there is little hope that this problem will be alleviated.[16]

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[15]U.S. Senate, Committee on Labor and Human Resources, 96th Congress, 2nd Session. *The Mental Health Systems Act Report No. 712 to Accompany S 1177.* Washington, D.C.: U.S. Government Printing Office, 1980, p. 52.

[16]In the 1980 National Health Planning Goals issued by the Health Resources Administration, a goal addresses—for the first time—the mental health needs of children (Goal III A.4: Child Mental Health).

A third factor is the patchwork Federal funding strategy that has been a part of the Community Mental Health Centers program since its inception. Originally, Congress expected that CMHCs would become self-sustaining entities through increased State and local support and third-party reimbursements. Therefore, the matching funds Congress made available to centers were both limited in scope and brief in duration.

Despite congressional intentions, State and local governments failed to contribute sufficient funding to develop centers in all catchment areas. To a large extent, this general lack of support resulted from the minor role given to States in deciding whether and where CMHCs should be established. This funding problem was exacerbated by the limited third-party payments available to centers under the Medicaid and Medicare programs and most private insurance plans.

The Federal solution to this dilemma has been to create various grant mechanisms that provide additional financial assistance to CMHCs, but restrict the amount and number of awards each center may receive. Under this system, grants for the initial CMHC operation are now available on an annual basis for up to 8 years. Federal contributions to the centers decline, however, over the 8-year period. Similar limitations are placed on continuation or maintenance grants and on financial distress grants.

As a result of this eclectic approach to funding, CMHCs spend a great deal of their time preparing grant applications and performing other financially and administratively burdensome activities. This, in turn, forces CMHCs to reduce the services they provide to their patients. Moreover, as Federal funding runs out, the CMHC concept begins to break down: inpatient and other profitable services are recommended more frequently, while services such as consultation and education and satellite clinics are reduced in both form and quality.

The Panel believes that a fourth factor responsible for the lack of adequate mental health services for children is the failure of DHHS, and NIMH in particular, to provide necessary direction and assistance. NIMH has not lived up to its responsibilities in several respects. For example, regulations regarding children's services—which NIMH helps to develop—are blatantly inadequate in providing Federal guidance on the content and delivery of children's mental health services.

NIMH also has not taken the lead in establishing a program of technical assistance related to children's mental health services. Although this can be explained somewhat by statutory limitations on the amount of funding that can be allocated for this activity, NIMH could have taken more initiative in this area. NIMH staff, for example, have not actively promoted the development of model treatment programs or disseminated information about programs that are successful.

In addition, NIMH has not developed in-service training programs to help increase CMHC staff capacity to serve infants, children, and adolescents. Yet such training is seriously needed by the many professionals without adequate backgrounds in child development, children's mental health problems, and accepted therapeutic interventions such as individual, group, or family psychotherapy, parental competence training, or psychopharmacology.

Finally, NIMH has not sponsored sufficient service-related research that deals specifically with neonates, severely emotionally disturbed children and adolescents, or chronically mentally ill children. This type of research is urgently needed for both preventive and treatment purposes.

PLAN OF ACTION

The ultimate goal of the Panel is to ensure that the mental health needs of all children and their families are met. This will require changes in the general health care system and the mental health care system, and in the relationship between the two.[17] The Panel's narrower and more immediate objective is the development, expansion, and improvement of services for infants, children, and adolescents provided through the mental health system. To accomplish this objective, the Panel proposes:

- expanding the availability of consultative, preventive, and therapeutic services to children of all ages, especially in rural and other underserved areas
- developing new mental health services in underserved areas and assuring the continuation of existing community mental health centers
- coordinating CMHC services with other health, education, and social service agencies serving children
- extending CMHC services into other appropriate federally supported programs serving children, including schools, and juvenile institutions
- requiring State mental health service planning for the special needs of infants, children, and adolescents as part of broader State planning efforts
- providing support for research and training activities in mental health services for children
- increasing Federal funding for mental health services for children

The Mental Health Systems Act[18] recently passed by Congress and signed into law establishes a general framework that is consistent with the Panel's recommendations. This legislation was designed, in part, to meet the mental health needs of children and other unserved and underserved populations in the United States. The Act:

- requires States to develop extensive mental health programs addressing the mental health needs of special groups
- creates several grant categories including grants for severely emotionally disturbed children and adolescents and chronically mentally ill individuals, as well as for prevention and linkage programs
- makes grant funds available to appropriate entities other than traditional CMHCs

[17]For a full description of the Panel's proposals for improvements in mental health services including those that are not focused on the CMHC Act and the Mental Health Systems Act, see chapters 5, 7, and 8 of volume I.

[18]P.L. 96-398 (to be codified in Title 42 U.S.C. Sect. 9401 *et seq.*).

In light of these legislative mandates, the Panel's Plan of Action focuses primarily on regulatory proposals to ensure that the new law will be implemented in ways that meet the mental health needs of children.

State Planning Activities

With regard to the implementing regulations for State mental health services plans or, as they are referred to in the Mental Health Systems Act, services programs, the Panel offers several recommendations. First, it urges that the Secretary of DHHS issue regulations mandating that States perform, as part of their general mental health service needs assessments, an assessment of the mental health needs of children for a full continuum of specialized services. These services should include prevention, early detection, and treatment of cognitive, emotional, and psychoneurological dysfunctions; family intervention and parental competence training; special schools; residential treatment services for adolescents; comprehensive community-based services for chronically emotionally ill children; and special treatment services for mentally retarded children who are emotionally disturbed. The statewide assessment should be based on needs assessments undertaken at the area level and conducted in cooperation with relevant local government agencies including maternal and child health agencies.

Second, the Panel recommends that regulations require each State to include in its State mental health services program a specific plan for meeting the special service needs of children through different therapeutic, consultative, and preventive strategies. This plan should be developed in coordination with State agencies responsible for health, education, family support, and, where appropriate, juvenile justice services for children, and should specify how mental health services would be integrated with these various service delivery systems.

A third recommendation is that States be required to identify current State and local budget allocations for children's mental health services as well as projected budgets for delivering new children's services. In this way, the contribution of the States and local communities can be properly evaluated.

Last, the Panel proposes that regulations require States to establish, in accordance with applicable regulations and guidelines prescribed by the Secretary of DHHS, mental health service standards including specific minimum standards for the delivery of children's services. In addition, States should be required to develop procedures for monitoring compliance with the standards they set. These standards and procedures should become part of the States' mental health services programs.

Regulatory Requirements for Grant Programs

With respect to the different grant programs, the Panel recommends that a number of regulatory proposals be adopted to ensure that the mental health needs of children are met adequately.

Operation Grants

For operation grants for new CMHCs and continuing CMHCs that have not exhausted 8 years of initial support, implementing regulations should mandate that Community Mental Health Center advisory boards include both lay persons and professionals with a demonstrated interest in providing mental health services to children. Moreover, these grant applicants should be required to specify how specialized services would be provided to children and adolescents within each of the six service categories mandated in the initial 3-year operation period under the Mental Health Systems Act. Applicants should be required to present a written justification if these services will not be made available. In addition, regulations should require potential grantees to identify the number of staff members and the amount of money that will be allocated to the delivery of children's services. They also should require potential grantees to document special efforts to identify and serve minority and low-income children. Identical implementing regulations should be adopted for maintenance grants to centers that are no longer eligible for operational support, but that need additional assistance to meet the costs of nonrevenue producing activities such as consultation and education and followup services.

Categorical Grants

Implementing regulations also are needed for the special categorical grant programs under the Mental Health Systems Act. These include:

- grants for services for severely mentally disturbed children and adolescents
- grants for services for chronically mentally ill individuals
- grants for the prevention of mental illness and the promotion of mental health
- grants for mental health services in health care centers
- grants for mental health services for elderly individuals and other priority populations
- grants and contracts for innovative projects
- grants for protection and advocacy programs

Although children should be served under every one of these programs, the Panel is suggesting specific regulatory proposals for the first four only. The Panel has chosen this approach with the expectation that these programs will have the most direct and, therefore, the greatest impact upon the delivery of mental health services to children.

Of particular concern to the Panel are the grants for services for severely mentally disturbed children and adolescents and the grants for chronically mentally ill individuals. It believes that the regulations pertaining to these grant categories must define chronically mentally ill individuals to include children and must distinguish these children from those who are severely emotionally disturbed. The Panel approaches this issue with a degree of caution because of the long-standing controversy surrounding definitions that tend to become labels. Nonetheless, it maintains that such definitions are necessary to ensure the adequate delivery of special services these children and adolescents need.

The Panel suggests that the regulations implementing the grant program for severely emotionally disturbed children define these children to include those who exhibit major impairment in basic age-expected personality functions where the primary cause for such impairment cannot be attributed to an organic condition. This definition would include children who have severe emotional disturbances in association with physical impairments or diseases. Regulations for the grant program for chronically ill individuals could define them to include children whose basic age-expected developmental functioning is impaired, as a result of either genetic or environmental factors, to a degree that has already shown evidence of developing into a pattern of chronic emotional disturbance which may place the child at risk of institutionalization.

Beyond definitional issues, the Panel's recommendations for these two categorical grant programs are similar. In both instances, regulations should require Community Mental Health Centers and other grantees to develop new services, where necessary, to fill the gaps in treatment modalities for these children. These services include support and counseling for families, the operation of special schools, and both short- and long-term residential treatment, especially for adolescents. Each of these services, of course, must be appropriate to the age-related needs of the children and adolescents involved. For children who are chronically mentally ill, regulations should require grantees to demonstrate that they are able to serve children and their families intensively and for long periods of time. Finally, under all circumstances, efforts should be made to coordinate these services with other service delivery systems for children.

As for the regulations pertaining to the prevention grant program, the Panel recommends that at a minimum, grantees be required to develop strategies for effecting institutional changes in the health, education, and juvenile justice systems that will result in more active community support for children's mental health services. Model projects should be established at sites where children are most often found, including nurseries, schools, health care programs, and drop-in centers for adolescents. These projects should focus on activities such as health promotion as well as primary prevention and early intervention. In the latter case, model projects should be designed to forestall chronically debilitating developmental circumstances by aiming a variety of resources at the populations at greatest risk during the prenatal period or immediately after birth.

Implementing regulations are also needed for grants for mental health services in health care centers ("linkage grants"). The Panel strongly urges that services for children and pregnant women be given special priority. Mental and physical health problems for both groups often are intricately intertwined. For children, these problems include the stress that may be attendant to normal development and the anxiety that may be associated with mental or physical handicaps. For pregnant and postpartum women, they involve the emotional stress that may accompany concerns about the health of the child or the competence of the mother, and in some instances they may involve behavior such as drug abuse which is harmful to fetal development.

The Panel recommends, therefore, that regulations establish Title V service providers, including Maternity and Infant Care (MIC) and Children and Youth (C&Y) projects, and especially crippled children's clinics, as preferred grantees. These providers are in a unique position to identify early impairments in physical or mental development that may indicate the need for counseling or mental health treatment.

General Guidelines

In addition to these regulatory proposals, the Panel believes that it is necessary for the Secretary of DHHS to issue guidelines that will further enhance the delivery of mental health services to children. Standards for children's treatment services should be included. These should specify that children's mental health services include a general health interview and, where appropriate, referral to a health provider for a further health assessment or treatment intervention. Referrals should be made to Title V agencies, Community Health Centers (CHCs) and other health providers, and children eligible for Medicaid should be referred to the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Such policies will help ensure that children with physical problems are not mistakenly diagnosed as learning disabled or emotionally disturbed. At the same time, referral procedures will promote greater cooperation between health and mental health professionals and encourage the development of a stronger cross-referral system.

Furthermore, these guidelines should encourage the child's parent or caretaker to participate in the development of treatment and followup programs and in the actual delivery of services which, to the extent possible, should be provided in the child's home or community. Guidelines should also encourage grantees to involve the various systems in which the child and his family function, including the education system and, where appropriate, the juvenile justice system.

Amendments to the Act

Despite the considerable advances made by the new Mental Health Systems Act, it does not go far enough in some respects in settling issues that concern the Panel. Consequently, the Panel is also proposing several legislative amendments to the Act for Congress' immediate consideration. If adopted in the near future, these amendments should take effect in FY 1982 when the Mental Health Systems Act becomes operational.

Program Funding

First, the Panel recommends that the Act be amended to increase authorizations for the various grant programs. Current authorizations are abysmally low. The authorization levels for services to severely emotionally disturbed children and adolescents, for example, rise from a mere $10

million in FY 1982 to only $15 million for FY 1984. It is certainly questionable how meaningful such authorizations can be nationally when the budget for just one program serving a city of slightly more than 700,000 persons for FY 1982 is approximately $3 million.[19] The Panel recommends, therefore, that by the end of FY 1984, $193 million be appropriated and applied to the four special categorical grant programs discussed in this Plan of Action. This figure represents an increase of $90 million over the amounts currently authorized for these grant programs for FY 1984 by the Mental Health Systems Act.[20] Such an increase undoubtedly will mean that a substantial number of additional children will be able to receive the special services they require.

Second, the Panel recommends that a statutory amendment be enacted that would eliminate the time limitation on grants for nonrevenue producing services, or "maintenance" grants, that each CMHC or other mental health service program may receive. To qualify for these grants, however, a center must agree to use its grant funds for nonrevenue producing activities including consultation and education, outreach, home-based services, followup and case management. In addition, the grantee must be willing to meet the cost of providing services to low- and moderate-income persons covered by Medicaid or private insurers. Because these activities and services will always be needed in the community, adequate funding for them should be provided on a continuing basis. While the Panel does not believe it likely that States and localities will be in a position to pick up the entire cost for these services and activities, it does believe that the responsibility for funding them should be a shared one. For this reason, the Panel proposes that centers be required to document that State and local matching funds of 50 percent are being used for the activities and services described above.

Research, In-Service Training, and Technical Assistance

Additional legislative revisions are needed to ensure that adequate research, training, and technical assistance activities related to the special mental health needs of children can be undertaken. The Panel recommends, that the Mental Health Systems Act be amended to permit the Secretary of DHHS to retain up to 5 percent of the total amount of funds appropriated under the various grant programs to be used for these purposes.

These programs should give special attention to the mental health needs of children. Research activities, for example, should be focused on the development of clinical techniques and service delivery strategies for

[19]The Program is the Division of Child and Adolescent Services at Saint Elizabeth's Hospital in Washington, D.C.

[20]Current authorizations for the four grant categories for the fiscal year ending September 30, 1984 are.

- grants for services for severely mentally disturbed children: $15 million
- grants for services for chronically mentally ill individuals: $60 million
- grants for the prevention of mental illness and the promotion of mental health: $8 million
- grants for mental health services in health care centers: $20 million

infants and young children at risk or with diagnosed emotional, cognitive, or psychoneurological developmental problems. Training programs should be designed to equip health care providers and educators, as well as the mental health staff itself, with the specialized knowledge and skills to treat children and their families effectively. These include an understanding of the emotional and cognitive problems of young children, skills for specific intervention strategies, and the ability to coordinate all available resources needed to assist children and their families.

Program Evaluation

The Panel's final legislative proposal calls for greater program evaluation. The Panel believes that a periodic assessment of the mental health services being provided to children is necessary to ensure that their mental health needs are met adequately. The Panel recommends, therefore, that the Secretary of DHHS be required by statute to report to Congress annually on the progress being made to extend appropriate mental health services to children of all ages. The report should include information concerning the type and number of services being provided; the extent to which these services are meeting identified needs; the standards used in providing these services; any service-related research findings generated through the activities of the various National Institutes; and the status of staff preparation and training.

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CHAPTER 7

OTHER MAJOR FEDERAL PROGRAMS AFFECTING MATERNAL AND CHILD HEALTH

Ten Federal programs, in addition to those described in detail in this volume, have played a particularly significant role in the delivery of health and health-related services to children and pregnant women. These programs provide not only health care services, but social and educational services as well. Their histories, purposes, and accomplishments are described briefly in this chapter. These programs, and the five already discussed, constitute the core of Federal health and health-related service activities for children and pregnant women.

COMMUNITY HEALTH CENTERS

Designed to provide health services and related training, the Community Health Centers (CHCs)[1] program was launched by the Office of Economic Opportunity in 1966 and subsequently authorized by Section 330 of the Public Health Service Act. Highest priority for funding was given to medically underserved areas, particularly those with high infant mortality rates, older populations, and shortages of health care personnel. The program focuses on comprehensive ambulatory care. Primary health services include physicans' services, diagnosis, treatment, diagnostic X-rays, laboratory services, and emergency medical care. Preventive services include prenatal and postpartum care, well-child care, children's eye and ear examinations, immunizations, preventive dental services, voluntary family planning services, health education, and nutrition assessments.

The Community Health Centers program is now administered by the Bureau of Community Health Services within the Health Services Administration. Some 858 CHCs (726 in rural areas and 132 in urban areas) served more than 3.864 million persons in 1979, including more than 1.603 million children. In addition, 112 Migrant Health Centers—

[1]Title 42 U.S.C. Sect. 254c (1976 & Supp. II 1978).

which provide similar services—served an estimated 1,052,000 migrant and seasonal workers, including approximately 221,900 children. In FY 1980, rural and urban health centers were funded at $320 million, and the migrant centers at $39 million.

The centers have demonstrated measurable success. In a study of centers in 13 cities, hospitalization, for example, was reduced 25 percent for center users, compared with nonusers.[2] Nevertheless, there is a continuing need for greater access to primary and preventive care services in underserved areas as well as for more coordination between the centers and other sources of Federal and State funding, such as Medicaid, Community Mental Health Centers, and family planning services.

TITLE XX

Enacted in 1965, Title XX[3] of the Social Security Act provides grants to the States for the provision of social and support services to low- and moderate-income families. States may provide many health and health-related services, such as family counseling and other mental health services, support services to developmentally disabled, blind, and physically handicapped individuals, services to expectant parents, transportation to health service providers, early and periodic health screening and diagnosis for children not eligible for Medicaid, family planning services, and child day care. The program is operated under the Administration for Children, Youth, and Families. The Federal appropriation for Title XX was $2.7 billion in FY 1980, and according to agency projections, expenditures for services to children accounted for about 62 percent of the total.

Child day care services are provided with Title XX funds in all States and the District of Columbia. Day care centers and licensed day care homes receiving Federal aid through Title XX are significant avenues for improving the delivery of health services to young children. Some 18,300 centers serve about 870,000 children a year with Title XX funds. They are subject to Department of Health and Human Services (DHHS) regulations stipulating that children must receive comprehensive health assessments and have appropriate immunizations, and may be provided transportation to continuing health services.

Title XX family planning services are provided in the District of Columbia and in all States but one. Most States offer information on the availability of family planning resources, referral, and education and counseling on contraceptive methods. Most also provide direct medical services, including diagnosis, treatment, drugs, and contraceptive supplies and devices furnished by or under the supervision of a physician. About 1.4 million persons received Title XX family planning services in FY 1979.

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[2]Okada, L. and T. Wan. "Patterns of Health Services Utilization in Urban Low-Income Areas." Paper presented to the Institute of Management/Science Operations Research Society of America. Joint National Meeting, April 30–May 2, 1979.

[3]Title 42 U.S.C. Sect. 1397 *et seq.* (1976 & Supp. II 1978).

TITLE X FAMILY PLANNING SERVICES

Title X of the Public Health Services Act, authorizing Family Planning Services and Population Research,[4] was enacted in 1970 because of the high number of unintended pregnancies among the poor. Its purpose is to make comprehensive voluntary family planning services available to all persons requesting them, but the emphasis is on providing services to low-income women and adolescents. Indeed, regulations clearly instruct grantees to make certain no one is denied services because of an inability to pay.

The program provides counseling, contraception services, voluntary sterilization, pregnancy testing, health information, screening and referral, and general community education. Administered by the Bureau of Community Health Services within the Health Services Administration, Title X helps fund some 3,000 agencies across the United States to run 5,125 family planning programs. In FY 1980, funding was $162 million, and organized family planning programs served 4.4 million low- and marginal-income women, including 2.8 million adults and 1.6 million teenagers. By comparison, in 1966, before significant Federal support for family planning services, only 400,000 women received services in family planning clinics. Nevertheless, approximately 3 million adult women and 1.8 million teenagers still need subsidized family planning services.

Title X-funded family planning programs deserve at least partial credit for the decline in the number of unwanted pregnancies in the past few years among groups who previously had the highest rates of unintended births—minorities, the poor, and the least educated. This in turn has helped to reduce the Nation's infant mortality rate.

ADOLESCENT PREGNANCY

Despite its comprehensive title, the Adolescent Health Services, Pregnancy Prevention, and Care Act of 1978[5]—known generally as the adolescent pregnancy program—focuses on services for pregnant adolescents, adolescent parents, and their infants. Adolescents who are pregnant or who are parents are eligible for pregnancy testing, prenatal and postnatal care, family planning services, venereal disease screening and treatment, sex and family life education, and a variety of counseling services related to pregnancy, parenthood, and education, as well as employment. By contrast, adolescents who are not already pregnant or parents are eligible only for sex education, counseling, referral, and pregnancy testing.

The program is administered under the Office of the Assistant Secretary of Health. Congress authorized $75 million for this program for FY 1981, but in the past, the amounts actually appropriated have been significantly lower: in FY 1980, for example, only $7.5 million was appropriated. There

[4]Title 42 U.S.C. Sect. 300 (1976 & Supp. II 1978).

[5]Title 42 U.S.C. Sect. 300a-21 (Supp. II 1978).

were only four adolescent pregnancy programs in 1979, and in FY 1980 27 new grants were awarded. But 300 communities had submitted applications and gone through the process of coordinating their related services as a prerequisite to receiving funds. (All programs are mandated to have established linkages with existing resources.) Grantees include schools, health agencies, advocacy groups, and community action agencies.

There is widespread agreement that the legislation was based on insufficient data—not only to justify needed funds but also to identify the minimum services that should be required. Yet the need for a program to address the problem of unwanted pregnancy among adolescents is immense. About 17 percent of all infants born in 1977 were born to teenagers; the Centers for Disease Control have estimated that 46 percent of teenage births and 70 percent of all teen pregnancies that year were unintended.[6]

GENETIC SCREENING

The National Genetic Diseases Act,[7] Title IX of the Public Health Services Act, which is administered by the Office for Maternal and Child Health within the Bureau of Community Health Services, provides funds to States for programs of genetic screening, counseling, and referral for treatment. These programs offer comprehensive screening services for sickle cell anemia, Cooley's anemia, Tay-Sachs disease, and other genetic disorders. Funds are also used to support laboratory testing, diagnosis, and information and educational services. Some selected services include newborn screening for metabolic disorders, counseling, the preparation of educational materials for health providers and the public, and the design of model curricula on genetics for school-age children.

In FY 1980, only $11.5 million was appropriated for the program, yet the cost of genetic disease to society is enormous. About 30 percent of all hospitalized children have diseases that are at least partially genetic in origin. The cost of caring for persons suffering from Down's Syndrome, for example, is estimated to be $1.7 billion a year.

SIDS

The Sudden Infant Death Syndrome (SIDS) program,[8] included in the 1978 amendments to Title IX of the Public Health Service Act, was initiated to help combat a disorder that claims the lives of 6,000 to 7,000 infants each year who die suddenly, quietly, and unexpectedly during apparently normal sleep. SIDS is the leading cause of death between the ages of 1 and 12 months and is responsible for half of all deaths during that time. The SIDS program, administered by the Office for Maternal and

[6]U.S. Department of Health and Human Services, Center for Disease Control. "Teenager Childbearing and Abortion Patterns—United States, 1977." *Morbidity and Mortality Weekly Report* 29: 157, 159, April 11, 1980.

[7]Title 42 U.S.C. Sect. 300b (1976 & Supp. II 1978).

[8]Title 42 U.S.C. Sect. 300c–11 (1976 & Supp. II 1978).

Child Health, funds 42 projects in over half of the States to provide counseling and information services and to carry out data-gathering activities. It also conducts more than 2,000 educational programs each year. Funding for FY 1980 was $2.8 million. An additional $11 million was allocated within the budget of the National Institute of Child Health and Human Development for research into the sudden infant death syndrome.

HEAD START

Among the Federal Government's most successful child development efforts is its Head Start program[9] for low-income preschool children. Started by the Office of Economic Opportunity in 1965, and legislated under Title V-A of the Economic Opportunity and Community Partnership Act in 1967, the Head Start program to date has served 7.8 million children.

Now administered by the Administration for Children, Youth, and Families within the Office of Human Development Services, Head Start is designed to enhance a child's competency through education, health and social services, and parental involvement. It presently serves 378,000 preschool children in more than 9,200 centers (including centers located in urban ghettos, rural areas, Indian reservations, and migrant camps) throughout the Nation, with a budget of $735 million. Its health component consists of medical, dental, nutritional, and mental health services, with a broad range of preventive, diagnostic, treatment, and rehabilitative services.

Head Start has been shown to improve children's health: children who participate in Head Start have fewer cases of anemia, more immunizations, better nutrition, and better health in general than do children with similar backgrounds who do not participate. In addition, where there is a high degree of parental participation in the program, children gain in their social development.

DEVELOPMENTAL DISABILITIES

The Developmental Disabilities Service Act[10] was established to provide and coordinate services for persons suffering from certain chronic disabilities whose needs span several service areas, including health, education, social welfare, and rehabilitation. An estimated 5.6 million mentally retarded persons were originally eligible for the program. But recent amendments to the authorizing legislation have limited eligibility to individuals who have a severe chronic disability that is attributable to a mental or physical impairment, is manifested by age 22 and is likely to continue, results in substantial functional limitations, and indicates the need for a combination of special services. This shift to a functional

[9]Title 42 U.S.C. Sect. 2928 (1976 & Supp. II 1978).

[10]Title 42 U.S.C. Sect. 2661 *et seq.* (1970 & Supp. IV 1974).

definition of eligibility with a focus on severe retardation has reduced by more than one-third the number eligible, to an estimated 3.4 million persons.

The program is operated by the Developmental Disabilities Administration within the Office of Human Development Services. Grant funds are targeted at rural and urban poverty areas, with the bulk of the funds distributed to State-designated agencies providing priority services. These include alternative community living arrangements, nonvocational social development, case management, and child development. States receiving grants must spend a specified percentage of their awards on deinstitutionalization. Funding for FY 1980 was $62.4 million, which provided direct assistance to about 300,000 persons.

DISABLED CHILDREN'S PROGRAM

The Supplemental Security Income Disabled Children's program[11] provides referral and direct services for blind and disabled children receiving supplemental security income benefits under Title XVI of the Social Security Act. Medical, educational, social, and rehabilitative services are covered under the program, which is administered by the Office of Maternal and Child Health. Regulations provide for case management, a written Individualized Service Plan for each child, and necessary supportive services. Funding is based on formula grants to designated State agencies (46 States use the Crippled Children's Agency). For FY 1980, $19.8 million was distributed to serve approximately 209,000 children.

PROGRAMS OF THE CENTERS FOR DISEASE CONTROL

The Centers for Disease Control (CDC) in the Public Health Service provide a variety of services[12] related to maternal and child health through various centers and divisions. The Center for State Services, for example, gives technical assistance to State and local health departments for venereal disease and tuberculosis control procedures, and makes grants to States to provide vaccine in public clinics and schools. The Division of Environmental Health Services provides personnel to States for rodent control and awards funds to small and medium-sized cities for fluoridation as well as to local and city health departments to screen children for lead poisoning. In addition, personnel from the Center for Epidemiology are sent all over the Nation to investigate epidemic outbreaks. The Family

[11] Title 42 U.S.C. 1381 *et seq.* (1976 & Supp. II 1978).

[12] The authorization for each of the service programs described in this paragraph is found in Sections 317 and 318 of the Public Health Service Act. All are codified within Title 42 of the United States Code (1976 & Supp. II 1978) at the following sections: venereal disease control (Sect. 247b), tuberculosis control (Sect. 247b), vaccinations (Sects. 247b and 247b note), rodent control (Sects. 247b and 254c), fluoridation (Sect. 300f *et seq.*), lead-based paint poisoning control (Sect. 4801 et seq.), family planning (Sect. 300a), alcohol and smoking prevention (Sect. 2688e *et seq.*), and health curricula (Sect. 300u).

Planning Division performs epidemiological surveillance of abortions, assesses various family planning techniques, and conducts studies on birth defects. Grants for educational programs, such as alcohol and smoking prevention, are made under the auspices of the Center for Health Education, which is also responsible for developing health curricula for elementary schools.

The Centers' programs save lives and money; a major study[13] showed that $180 million spent on measles vaccination programs from 1966 to 1974, for example, saved $1.3 billion in medical and long-term health care costs by reducing deafness, mental retardation, and other problems. The CDC budget for FY 1980 was $295.7 million.

CONCLUSION

It is clear from this brief review of ten Federal programs that, in addition to the five programs discussed in previous chapters, there are various other potential avenues for improving child health—through direct services to pregnant women, infants, and children, through social service and public education programs, through programs addressing the environmental and behavioral components of health, and through programs intended to reduce the number of unwanted pregnancies. These additional programs have many service components and goals similar to those of Title V, Medicaid, WIC, P.L. 94–142, and the recent mental health systems legislation. The program philosophy and strategies urged throughout this volume should be applied to all 15 programs, even though the Panel has devoted special attention to a subset of them.

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APPENDIXES

APPENDIX A

SUMMARY OF MAJOR FEDERAL PROGRAMS PROVIDING HEALTH AND HEALTH-RELATED SERVICES TO CHILDREN AND PREGNANT WOMEN

I. HEALTH PROGRAMS

A. HEALTH FINANCING PROGRAM

1) Medical Assistance Program (Medicaid)

Placement: Health Care Financing Administration, Department of Health and Human Services.

Description: Formula grants under the Social Security Act to provide financial assistance to States for payments of medical assistance on behalf of cash assistance recipients and, in certain States, on behalf of the medically needy. Includes the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT). EPSDT provides preventive health care to children in low-income families by identifying, diagnosing, and treating medical, developmental, and dental problems.

Legislation: Title XIX, as amended by P.L. 88–97, P.L. 90–248 P.L. 91–56, P.L. 92–223 P.L. 92–603, P.L. 93–66, and P.L. 93–233.

Funding: FY 1980 Appropriations: $14.155 b.

B. MATERNAL AND CHILD HEALTH CARE

1) Title V

Placement: Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.

Description: Formula and project grants to States for maternal and child services to improve the health of mothers and children and to reduce the incidence of mental retardation and infant and maternal mortality. Services included are family planning, maternity, well-child, pediatrics and special child health services, early detection, prevention, and after care. Formula and project grants to States for training personnel in health care of and related services to mothers and children; particularly mentally retarded and multiply-handicapped children. Research provides project grants to support research in health services for mothers and children. Formula and project grants to States for crippled children's services to extend and improve medical and related health services to chronically ill and handicapped children.

Legislation: Social Security Act, Title V, as amended.

Funding: FY 1980 Appropriations: $376.3 m.

2) Sudden Infant Death Syndrome Information and Counseling

Placement: Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.

Description: Project grants to support the collection and analysis of data relating to the causes of sudden infant death syndrome, to provide information and counseling to families, and to educate health officials, emergency care providers, and the general public.

Legislation: Public Health Service Act, Title XI, as amended by P.L. 93–270 and P.L. 95–613.

Funding: FY 1980 Appropriations: $2.8 m.

3) Genetic Diseases Testing and Counseling Services

Placement: Bureau of Community Health Services, Health Services Administration, Department of Health and Human Services.

Description: Project grants to assist State and local governments as well as public and private nonprofit organizations in establishing and operating voluntary screening, diagnostic, laboratory, and counseling programs. The Sickle Cell Anemia Program is included in this program.

Legislation: P.L. 95–626; Health Services and Centers Amendments of 1978 which amends Title XI, Part A of the Public Health Service Act.

Funding: FY 1980 Appropriations: $11.57 m.

4) Supplemental Security Income Disabled Children's Program

Placement: Office for Maternal and Child Health Services, Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.

Description: Formula grants to States based on the State child population. These grants support special health, education, social service, and vocational rehabilitation services to disabled children under 16 years of age.

Legislation: Social Security Act, Title XVI.

Funding: FY 1980 Appropriations: $19.8 m.

5) Adolescent Pregnancy Program

Placement: Office of Adolescent Pregnancy, Office of the Assistant Secretary of Health, Public Health Service, Department of Health and Human Services.

Description: Project grants to provide comprehensive services to pregnant adolescents, adolescent parents, and some teenagers at risk. The emphasis is on teenagers 17 and under.

Legislation: Health Services Amendments of 1978, Titles IV, VII, and VIII, P.L.95–626.

Funding: FY 1980 Appropriations: $7.5 m.

6) Childhood Lead-Based Paint Poisoning Prevention

Placement: Centers for Disease Control, Public Health Service, Deparment of Health and Human Services.

Description: Project grants to provide for the development of comprehensive lead-based paint poisoning programs, detection and treatment of lead-based paint poisoning, and educational programs about the hazards of lead-based paint.

Legislation: Lead-Based Paint Poisoning Prevention Act, Title I; P.L. 91–695, as amended by P.L. 93–151, P.L. 94–317 and P.L. 95–626.

Funding: FY 1980 Appropriations: $11.25 m.

7) Comprehensive Hemophilia Diagnostic and Treatment Centers

Placement: Office for Maternal and Child Health, Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.

Description: Project grants to initiate or expand regionalized comprehensive diagnostic and treatment centers for hemophiliac patients stressing individual care plans and home care.

Legislation: Public Health Service Act; P.L. 78–410, Title XI, as amended.
Funding: FY 1980 appropriations: $3.0 m.

C. FAMILY PLANNING

1) Title X

Placement: Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.
Description: Project grants to provide education and comprehensive medical and social services to individuals seeking family planning services. Also, under special projects, training grants and contracts.
Legislation: Public Health Service Act, Title X; P.L. 95–83.
Funding: FY 1980 Appropriations: $162.0 m.

D. GENERAL HEALTH AND MENTAL HEALTH CARE

1) Community Health Centers

Placement: Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.
Description: Project grants to support the development and operation of community health centers which provide primary, supplemental, and environmental health services to medically underserved populations.
Legislation: Public Health Service Act; P.L. 95–626 as amended by Title I, P.L. 95–83, as amended by Title V, P.L. 94–63.
Funding: FY 1980 Appropriations: $320.0 m.

2) National Health Service Corps

Placement: Health Services Administration, Public Health Service, Department of Health and Human Services.
Description: Provides specialized services through assignment of personnel to communities that request to be designated critical health personnel shortage areas. Medical and dental care may be provided at a reduced rate or at no charge to qualifying persons.
Legislation: Public Health Service Act; P.L. 78–410, as amended.
Funding: FY 1980 Appropriations: $74.1 m.

3) Health Incentive Grants for Comprehensive Public Health Services

Placement: Centers for Disease Control, Public Health Service, Department of Health and Human Services.

Description: Formula and health incentive grants to assist State health authorities in providing comprehensive public health services.
Legislation: Public Health Service Act, Title III.
Funding: FY 1980 Appropriations: $68.0 m.

4) Disease Prevention Grants

Placement: Centers for Disease Control, Public Health Service, Department of Health and Human Services.
Description: Project grants to assist States in supporting a disease control program designed to contribute to national protection against diseases, including tuberculosis, rubella, measles, poliomyelitis, diphtheria, tetanus, and mumps.
Legislation: Public Health Service Act, as amended by the Disease Control Amendments of 1972; P.L. 92–449, Disease Control Amendments of 1976; P.L. 94–317 and P.L. 95–626.
Funding: FY 1980 Appropriations: Venereal Diseases, $47.62 m.; Immunization, $30.34 m.; Fluoridation, $6.79 m.

5) Community Mental Health Centers

Placement: National Institute of Mental Health; Alcohol, Drug Abuse, and Mental Health Administration; Public Health Service; Department of Health and Human Services.
Description: Project grants to support comprehensive mental health services including day care and specialized services for the mental health of children.
Legislation: Community Mental Health Amendments of 1975, Title III; P.L. 94–63.

E. HEALTH CARE FOR SPECIAL POPULATIONS

1) Migrant Health Grants

Placement: Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.
Description: Project grants and contracts to public or nonprofit agencies to support the development and operation of migrant health centers. They also support projects which provide primary ambulatory and inpatient, environmental and supplemental health services which are accessible to migratory and seasonal workers.
Legislation: Public Health Service Act, Title III, P.L. 95–626.
Funding: FY 1980 Appropriations: $39.7 m.

2) Indian Health Services

Placement: Indian Health Service, Health Services Administration,

Public Health Service, Department of Health and Human Services.

Description: Project grants to build the capabilities of tribes to staff and manage their health programs. Available only to federally recognized tribes and tribal organizations.

Legislation: Act transferring responsibility for health services from the Bureau of Indian Affairs to the Public Health Service; P.L. 83–568.

Funding: FY 1980 Appropriations: $547.21 m.

3) Appalachian Health Program

Placement: Appalachian Regional Commission.

Description: Project grants to provide a flexible, noncategorical approach to the development of health demonstration projects through community planning on a multicounty basis and implementation of that planning through service.

Legislation: Appalachian Regional Development Act of 1965, Sections 202 and 214, as amended; P.L. 89–4.

Funding: FY 1980 Expenditures: $18.01 m (Appropriations not earmarked for Health Program).

4) Health to Underserved Areas Program

Placement: Bureau of Community Health Services, Health Services Administration, Public Health Service, Department of Health and Human Services.

Description: Project grants to integrate primary care services into a system of rural health care delivery and to develop mechanisms to provide better health care to rural people, including those eligible for Medicaid.

Legislation: Social Security Act, Title XI, Section 1110.

Funding: FY 1980 Appropriations: $14.0 m.

5) Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)

Placement: Office of Assistant Secretary of Defense for Health Affairs, Department of Defense.

Description: Direct payment for specified uses to provide medical care in civilian facilities.

Legislation: Military Medical Benefits Act of 1966, as amended.

Funding: FY 1980 Appropriations: $736.0 m.

6) Uniformed Services Health Benefits Program

Placement: Office of Assistant Secretary of Defense for Health Affairs, Department of Defense.

Description: Direct provision of medical care to active duty uniformed services personnel and their dependents.

Legislation: Military Medical Benefits Act of 1966, as amended.
Funding: FY 1980 Appropriations: $3.864 b.

II. HEALTH-RELATED PROGRAMS

A. NUTRITION PROGRAMS

1) Special Supplemental Food Program for Women, Infants, and Children (WIC)

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Grants to States for projects to supply supplemental nutritious foods and nutrition education to participants identified to be nutritionally at risk because of inadequate income and inadequate nutrition.
Legislation: Child Nutrition Act of 1966 as amended; P.L. 95–627.
Funding: FY 1980 Appropriations: $758.0 m.

2) Food Stamps

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Direct payments to low-income households for specified use to improve their diets by supplementing their food purchasing ability. Also, Federal Support for State Administrative costs incurred.
Legislation: Food Stamp Act of 1964; P.L. 95–113.
Funding: FY 1980 Appropriations (includes Supplemental): $9.191 b.

3) Child Care Food Program

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants (also sale, exchange, or donation of property and goods) to assist public and nonprofit private organizations in maintaining or expanding nonprofit food service programs for children in nonresidential institutions providing child care.
Legislation: National School Lunch Act of 1966, Section 16, as amended by P.L. 94–105, P.L. 95–627.
Funding: FY 1980 Appropriations: $220.4 m.

4) School Breakfast Program

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants (also sale, exchange, or donation of property and goods) to reimburse public and nonprofit private schools for nutritious breakfasts for school children.
Legislation: Child Nutrition Act of 1966, as amended; P.L. 94–105, P.L. 95–166, P.L. 95–627.
Funding: FY 1980 Appropriations: $261.4 m.

5) Special Meal Assistance

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Free and reduced in-house prices for lunches to needy children.
Legislation: National School Lunch Act, as amended; P.L. 94–105, P.L. 95–627.
Funding: FY 1980 Appropriations: $1.381 b.

6) National School Lunch Program

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants (also sale, exchange, or donation of property and goods) to assist States in making the school lunch program available to school children.
Legislation: National School Lunch Act of 1966, as amended; P.L. 94–105, P.L. 95–166, P.L. 95–627.
Funding: FY 1980 Appropriations: $734.7 m.

7) Special Milk Program for Children

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants to encourage the consumption of fluid milk by children of high school grades and under through reimbursement to eligible schools and institutions which inaugurate or expand milk distribution services.
Legislation: Child Nutrition Act of 1966, as amended; P.L. 95–166.
Funding: FY 1980 Appropriations: $142.0 m.

8) Summer Food Service for Children

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants to States (also sale, exchange, or donation of property and goods) for maintaining and expanding nonprofit food service programs for children in service institutions and summer camps during the summer months.
Legislation: National School Lunch Act of 1966, Section 13; as amended by P.L. 94–105, P.L. 95–166, P.L. 95–627.
Funding: FY 1980 Appropriations: $88.8 m.

9) Nutrition Studies; Education and Training

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants to State educational agencies to provide for the nutrition-related training of educational and food service personnel, the food service management training of school food service personnel, and the conduct of nutrition education activities.

Legislation: Child Nutrition Act of 1966, Section 19, as amended; P.L. 95–166.
Funding: FY 1980 Appropriations: $21.7 m.

10) State Administrative Expenses for Child Nutrition

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants to provide State educational agencies with funds to cover administrative expenses for supervising and giving technical assistance to local school districts and institutions in their conduct of child nutrition programs.
Legislation: Child Nutrition Act of 1966, Section 7, as amended; P.L. 90–302, P.L. 91–248, P.L. 95–166, P.L. 95–627.
Funding: FY 1980 Appropriations: $34.87 m.

11) Equipment Assistance for School Food Service Programs

Placement: Food and Nutrition Service, Department of Agriculture.
Description: Formula grants to enable States to supply schools in low-income areas with equipment for storing, preparing, transporting, and serving food to children.
Legislation: Child Nutrition Act of 1966 as amended; P.L. 95–166, P.L. 95–627.
Funding: FY 1980 Appropriations: $20.0 m.

12) Regional Commission Health and Nutrition Demonstration Projects

Placement: Coastal Plains, Four Corners, Ozarks, Upper Great Lakes, and Old West Regional Commissions.
Description: Project grants for planning, construction, equipment, and operation of multicounty demonstration health and nutrition projects.
Legislation: Public Works and Economic Development Act of 1965, Title V, Section 516, P.L. 89–136 as amended by P.L. 94–185.
Funding: FY 1980 Appropriations: $5.39 m.

13) Community Food and Nutrition

Placement: Community Services Administration.
Description: Project grants, contracts, and training to supplement, extend, and broaden other food programs and to provide, on an emergency basis, food to low-income families or individuals.
Legislation: Economic Opportunity Act of 1964, Title II, as amended; P.L. 95–568.
Funding: FY 1980 Appropriations: $27.0 m.

B. CHILD DEVELOPMENT AND EDUCATION PROGRAMS

1) Head Start

Placement: Administration for Children, Youth, and Families, Office of Human Development Services, Department of Health and Human Services.

Description: Project grants to provide comprehensive health, educational, nutritional, social, and other services to children, primarily 3 years old to school age, and their families who are economically disadvantaged. Parental involvement is emphasized.

Legislation: Head Start Economic Opportunity and Community Partnership Act of 1974; P.L. 93–644, Title V, Part C, as amended.

Funding: FY 1980 Appropriations: $735.0 m.

2) Follow Through

Placement: Office of Elementary and Secondary Education, Department of Education.

Description: Formula grants and project grants to sustain and augment in primary grades, the gains made by children of low-income families in Head Start. Children receive special instruction, health, nutrition, and other services. Parental involvement is stressed.

Legislation: Economic Opportunity Act of 1964, as amended by P.L. 95–568, Economic Opportunity Amendments of 1978.

Funding: FY 1980 Appropriations: $44.25 m.

3) Educationally Deprived Children of Migrants

Placement: Division of Migrant Education, Office of Elementary and Secondary Education, Department of Education.

Description: Formula grants to State educational agencies to expand and improve programs to meet the needs of migratory workers and fishermen. Programs include remedial instruction, health, nutrition, psychological services, cultural development, and prevocational training.

Legislation: Elementary and Secondary Education Act of 1965 as amended; P.L. 89–10 and P.L. 89–750, as amended by P.L. 95–561.

Funding: FY 1980 Appropriations: $245.0 m.

4) Improvement in Local Educational Practice

Placement: Office of Elementary and Secondary Education, Department of Education.

Description: Formula grants to local educational agencies to improve their educational practices, including health and nutrition

programs. Fifteen percent is set aside for children with special needs and handicapped children or those with learning disabilities.

Legislation: Elementary and Secondary Education Act, Title IV, as amended by P.L. 95–561.

Funding: FY 1980 Appropriations: $146.0 m.

5) Alcohol and Drug Abuse Education Program

Placement: Office of Educational Research and Improvement, Department of Education.

Description: Project grants used for developing problem-solving techniques to reduce alcohol and drug abuse. Designed to promote awareness and understanding of the problems and to treat causes rather than symptoms.

Legislation: Alcohol and Drug Abuse Education Act; P.L. 95–336.

Funding: FY 1980 Appropriations: $3.0 m.

6) Drug Abuse Education Programs

Placement: Alcohol, Drug Abuse and Mental Health Administration, Public Health Service, Department of Health and Human Services.

Description: Project grants to collect, prepare, and disseminate information dealing with the use and abuse of drugs and the prevention of drug abuse.

Legislation: Drug Abuse Office and Treatment Act of 1972; P.L. 92–255 as amended.

Funding: FY 1980 Appropriations: (Combined with Community Programs).

7) Cooperative Extension Service

Placement: Science and Education Administration, Department of Agriculture.

Description: Formula grants to States to provide educational programs including parent education and child development.

Legislation: Smith Lever Act as amended; Rural Development Act of 1972; Food and Agricultural Act of 1977.

Funding: FY 1980 Appropriations: $285.54 m. (Includes Expanded Food and Nutrition Education Program for low-income families, $51.81 m).

8) Appalachian Child Development

Placement: Appalachian Regional Commission.

Description: Funds to create State and sub-State capabilities in planning child development programs in order to provide services to underserved areas throughout the region and to test innovative projects and programs.

Legislation: Appalachian Regional Development Act of 1965, Section 202, as amended; P.L. 89–4.

Funding: FY 1980 Expenditures: $11.2 m. (Appropriations not earmarked for Child Development).

C. SPECIAL SERVICES FOR HANDICAPPED CHILDREN

1) Handicapped Preschool and School Programs

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Formula grants to States to assist in providing a free appropriate education to all handicapped children.

Legislation: Education of the Handicapped Act, Title VI, Part B as amended by P.L. 94–142, as amended by the Education Amendments of 1978.

Funding: FY 1980 Appropriations: State Grant Programs, 5–18 yrs. old, $874.50 m.; Preschool Incentive Grants, $25.0 m.

2) Handicapped Special Population, Early Childhood Education Program

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants to support experimental demonstration, outreach, and State implementation of preschool and early childhood projects for handicapped children and their parents from birth through 8 years of age.

Legislation: Education of the Handicapped Act, Title VI, Part C, as amended by P.L. 95–49.

Funding: FY 1980 Appropriations: $20.04 m.

3) Special Population Programs for the Severely Handicapped

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants and contracts to develop innovative approaches to education, training, and services to severely handicapped children and youth in deinstitutionalized or integrated settings.

Legislation: Education of the Handicapped Act, Title VI, Part C, P.L. 91–230.

Funding: FY 1980 Appropriations: $5.92 m.

4) Handicapped Regional Resource Centers

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants to pay all or part of the cost of establishing or operating regional resource centers to provide advice and technical services to educators to improve the education of the handicapped.

Legislation: Education of the Handicapped Act, Title VI, Part C; P.L. 91–230.

Funding: FY 1980 Appropriations: $9.76 m.

5) Handicapped Media Services and Captioned Films

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants to provide for acquisition and distribution of media materials and equipment, for research into use of media, and for training of teachers, parents, and others in media utilization. A free loan library service of captioned films is maintained.

Legislation: Education of the Handicapped Act, Title VI, Part F; P.L. 91–230, P.L. 94–142.

Funding: FY 1980 Appropriations: $19.0 m.

6) Handicapped Innovation and Development

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Grants and contracts for model programs, research, and development activities.

Legislation: Education of the Handicapped Act, Title VI, Part E, as amended by P.L. 95–49.

Funding: FY 1980 Appropriations: $19.91 m.

7) Handicapped Recruitment and Information

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants and contracts to enable public or private agencies or institutions to help parents and consumer groups provide information and referral services, to recruit potential teachers, and to encourage schools to respond to special needs of handicapped children.

Legislation: Education of the Handicapped Act, Title VI, Part D, P.L. 91–230.

Funding: FY 1980 Appropriations: $1.0 m.

8) Handicapped Special Education Personnel Development

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants to improve the quality of and increase the supply of regular educators, physical education or recreation teachers, paraprofessionals, and other support personnel to maintain handicapped children in an appropriate school setting.

Legislation: Education of the Handicapped Act, Part F, as amended by the Education Amendments of 1974 and 1976.

Funding: FY 1980 Appropriations: $55.38 m.

9) Education of the Handicapped Children in State-Operated or Supported Schools

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Formula grants to States to extend and improve comprehensive educational programs for handicapped children enrolled in State-operated or State-supported schools.

Legislation: Elementary and Secondary Education Act of 1965 as amended by P.L. 89–313, P.L. 93–380, P.L. 94–142.

Funding: FY 1980 Appropriations: $144.0 m.

10) Centers and Services for Those with Developmental Disabilities

Placement: Office of Human Development Services, Department of Health and Human Services.

Description: Project grants and formula grants to States to provide comprehensive services for persons with developmental disabilities, promote public awareness and provide information, improve quality and coordination of services, establish demonstration projects, and provide training for those working in developmental disability.

Legislation: Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963; P.L. 88–164, as amended by P.L. 91–517, P.L. 94–103, P.L. 95–602, Title V.

Funding: FY 1980 Appropriations: State Grants and Advocacy, $50.68 m.; Service Projects, $4.76 m.; University Affiliated Facilities, $7.0 m.

11) Centers and Services for Deaf-Blind Children

Placement: Office of Special Education and Rehabilitative Services, Department of Education.

Description: Project grants and contracts to support the establishment of model single and multi-State centers to provide deaf-blind children with comprehensive diagnostic and evaluation services, education and orientation programs, and effective consultive programs for their parents and teachers.

Legislation: Education of the Handicapped Act, Title VI, Part C.

Funding: FY 1980 Appropriations: $17.12 m.

12) Vocational Rehabilitation Services for Supplemental Security Income Beneficiaries

Placement: Office of Human Development Services, Department of Health and Human Services.

Description: Formula grants to States to provide necessary rehabilitative services to recipients of Supplemental Security Income (SSI) to enable them to attain or return to gainful employment.

Legislation: Social Security Amendments of 1972, Title XVI, Parts A and B; P.L. 92–603; P.L. 93–66, P.L. 93–233, P.L. 93–368, P.L. 94–556, P.L. 94–569, and P.L. 94–585.

Funding: FY 1980 Appropriations: $56.2 m.

D. SOCIAL SERVICES

1) Title XX

Placement: Office of Program Coordination and Review, Office of Human Development Services, Department of Health and Human Services.

Description: Grants to States for health and health-related services such as family counseling and mental health services, services for developmentally and physically handicapped, prenatal services for parents, transportation, screening and diagnosis of children not eligible for Medicaid, family planning services, and day care for children.

Legislation: Social Security Act, Title XX.

Funding: FY 1980 Appropriations: $2.7 b.

2) Child Welfare Research and Demonstration Projects

Placement: Children's Bureau, Administration for Children, Youth, and Families, Office of Human Development Services, Department of Health and Human Services.

Description: Project grants and research contracts to provide support for research and demonstration in child and family development and welfare, including "Education for Parenthood" and comprehensive programs for pregnant teenage girls.

Legislation: Social Security Act, Title IV–B.

Funding: FY 1980 Appropriations: $14.7 m.

3) Child Abuse and Neglect Prevention and Treatment

Placement: National Center for Child Abuse and Neglect, Office of Human Development Services, Department of Health and Human Services.

Description:	Project grants and research contracts to provide technical assistance to public and private nonprofit agencies and organizations; demonstration programs and projects to establish and maintain centers providing parent and self help, identification, and treatment of child abuse and to support research into the causes, prevention, and treatment of child abuse and neglect.
Legislation:	Child Abuse Prevention and Treatment Act, Title I, as amended; P.L. 93–247.
Funding:	FY 1980 Appropriations: $22.93 m.

APPENDIX B

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A number of people contributed to the Panel's work in reviewing and analyzing various Federal programs affecting maternal and child health. These include staff members of the Departments of Health and Human Services, Education, and Agriculture, State program officials, individuals associated with advocacy and professional organizations, and others with special knowledge of the policy and program issues surrounding the delivery of health services to children and pregnant women. All gave freely of their time and expertise. To each of them, the Panel wishes to express its profound gratitude.

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APPENDIX C

DISSENTING VIEWS

John MacQueen, M.D., Vice Chairperson
State Services for Crippled Children
University of Iowa

1. Dr. MacQueen dissents from the Panel's recommendation that the majority of members on the proposed State Maternal and Child Health Councils be consumers, or nonhealth professionals. (Chapter 2: Title V.)
2. Dr. MacQueen also disagrees with the recommendation that the Title V formula grant to States be awarded as a single grant, with funds for Maternal and Child Health and Cripped Children's services combined. (Chapter 2: Title V.)

John Palmer, Ph.D.
Assistant Secretary for Planning and Evaluation
Department of Health and Human Services

1. Dr. Palmer dissents from the Panel's recommendation regarding the formula by which Title V funds would be apportioned between Federal and State functions. In particular, he believes that because the proposed mechanisms for accountability are untested and there traditionally is a reluctance to withhold formula grant funds from States, a significant portion of any new funds appropriated to Title V should be distributed as discretionary incentive grants to States. (Chapter 2: Title V.)
2. Dr. Palmer also disagrees with the recommendation that the Bureau for Maternal and Child Health Services be created by legislation, as he believes that such matters should be left to the discretion of the Secretary. (Chapter 2: Title V.)

Charlotte Wilen
Founding Chairperson, Council on Maternal and Infant Health
State of Georgia

1. Mrs. Wilen, like Dr. MacQueen, dissents from the recommendation that there be a majority of consumers on the proposed State Maternal and Child Health Advisory Councils. She believes the Health Systems Agencies are the appropriate vehicle for consumer input. In her view, the State councils should be comprised of members of various professions providing maternal and child

health care, assuring an equal number of public and private health care consumers to the number of physicians from the public, private, and academic health arenas. Members should also represent nutrition, social work, hospital administration, and education. (Chapter 2: Title V.)

2. Mrs. Wilen objects to the Panel's statement that the Title V funding formula unfairly favors rural States over large industrial States, citing a recent survey conducted by the Alabama director of Maternal and Child Health which suggests that the costs of providing health care in rural areas are considerably higher than in urban areas. Accordingly, she objects to the recommendation that the formula be revised in order simply to reflect relative need among the States. (Chapter 2: Title V.)

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